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Addressing Fetal Alcohol Spectrum Disorder:
problem intractability and the search for solutions

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ABSTRACT

The scientific evidence base for Fetal Alcohol Spectrum Disorder (FASD) has rapidly advanced over the past four decades, but attempts to redress the problem have neither significantly reduced alcohol consumption by pregnant women nor addressed the lifetime consequences of FASD for individuals living with FASD or their families. This thesis seeks to explain why the problem of FASD appears so resistant to solution. FASD is characterised by complexity, ambiguity, a lack of agreement on definition and solutions, and resistance to traditional linear solutions: it is a wicked problem.

Stakeholders engaging with wicked problems bring diverse frames of reference and preferred definitions of the problem and its solution. The level of contestability and who dominates determines the selected strategy, which may be authoritative, collaborative or competitive.

Using a multiple method approach, this research uses archival records and qualitative data from semi-structured interviews, first to tell the story of FASD in the United States of America, Canada and Australia, and then to determine any similarities and differences in public policy approaches over the past forty years. The research finds that those who originally demanded attention to FASD expanded their group to engage those with the status and authority to influence policy solutions. In all countries, privileged medical and academic elites are endowed with technical authority, and their preferred solutions require the problem to be fragmented into measurable parts, with a focus on building an evidence base. FASD is now on governments' formal agendas, but attempts to manage FASD have led to authoritative policy solutions. Original demands have not been addressed: instead, government policy decision-making controls the entry of the problem into the public arena. This research proposes that this is influenced by the overarching problem of alcohol harms in societies where alcohol use is socially and culturally accepted.

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I sincerely thank my husband Noel and my family, who have patiently supported me to fulfil this goal; and those colleagues who work in the Fetal Alcohol Spectrum Disorders arena both in Australia and overseas, for their continued interest and encouragement.

I trust I am not the last member of a large and extended family in NW Tasmania to aspire to achieve academically.

NB: The spelling of fetal or fetus and foetal or foetus appear in the text of this thesis. The spelling of fetal has been adopted as the accepted technical term.

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CHAPTER 1 INTRODUCTION

Alcohol misuse is a serious, global public health issue ‘that can result in a wide range of physical, psychological, and social problems affecting the individual, the family, and the community’ (Barry et al. 2009, p. ii). The social and cultural acceptance not just of the use of alcohol but, more profoundly, its acceptable misuse, provides a fundamental challenge to changing public attitudes and behaviours related to alcohol. There are very real social, health, economic and judicial implications for both the users of alcohol and the wider community.

Alcohol use in pregnancy and the risk this poses to otherwise normal fetal development is one such harm. It is a problem which has captured increasing global attention, yet action to address the lifetime disability now known as Fetal Alcohol Spectrum Disorder (FASD), and effectively preventing or reducing this significant public health issue, has been paradoxically slow. Complicating the policy challenge is FASD prevention, which requires, in the absence of evidence of a minimal dose that causes fetal harm, an abstinence approach.

Social issues are almost always complex, and there is little doubt that the prevention of FASD poses particular challenges. At its core lies a legal, highly accessible and widely used drug – ethanol alcohol – that is perceived differently by the public than other drugs, both licit and illicit. It is generally estimated that FASD affects at least 1 in 100 live births (Jonsson, Salmon & Warren 2014). The FASD prevalence estimate for Canada is 1:100 live births (Popova et al. 2013, p. 14), while in the United States a midpoint range of 3.6 per cent of first grade children in the Midwestern United States has been estimated as having FASD (May et al. 2014). In Australia, a prediction of 2 per cent of the population has been made (McLean & McDougall 2014, p. 4). An average of these three estimates is 2.2 per cent of live births, which could mean that over 5,500 Australian children born each year are exposed to alcohol *in utero*.

With an annual cost disability services for those living with FASD estimated to be at least \$1.8 billion in 2013, the prevalence of FASD among special populations in Northern Canadian isolated communities has been reported to be much higher (Popova et al. 2013, p. 14). In Australia, an incidence of 1 in 8 children born for Fetal Alcohol Syndrome was found in one region of Western Australia (Laurie 2015). To date, studies have found higher rates among Indigenous than non-Indigenous Australians, but as there are no national estimates of the prevalence of FASD-related conditions in Australia, estimating prevalence needs to be managed with greater sensitivity. Nevertheless, alcohol use by women and girls in their childbearing years is the primary contributing factor, and the selective focus of public policy.

Despite scientific advances that inform policy, traditional methods of problem solving have not been successful. Attempts to stop or slow the impact of FASD have focused on high-risk drinking women, and specifically on First Nation or Indigenous women. Yet women of childbearing age across all sectors of Western society continue to consume alcohol at high and low risk levels: some have unintentionally consumed alcohol prior to pregnancy confirmation, some have elected to continue to consume some amount of alcohol during pregnancy, and some have found abstinence too difficult. Approximately 50 per cent of pregnancies are unplanned, and a recent study found between 40 and 80 per cent of pregnant women consume some amount of alcohol, many in the first trimester before pregnancy is confirmed (O’Keeffe et al. 2015).

The results of the 2010 Australian National Drug Strategy Household Survey indicate a reduction in alcohol consumption during pregnancy over the past decade. About half (51%) of women who were pregnant in the year prior to the survey reported drinking alcohol during pregnancy, most before they knew they were pregnant (Australian Institute of Family Studies 2012). In a 2015 report, the number of women not consuming alcohol in pregnancy had increased from 48.7 to 52.8 per cent from 2010 to 2013 (Australian Institute of Family Studies 2015). The data reveals approximately 42 per cent of Australian women used some amount of alcohol during pregnancy.

My understanding, knowledge and experience of the management of FASD as a public policy issue in Australia is grounded in my employment over the past decade, which provided a unique opportunity to gain insight into the lived experiences of those directly affected by FASD. As the manager of a national non-government service specific to this problem, I had various national participatory opportunities that provided insights into the multiple lenses through which FASD can be perceived and into how the Australian policy approach to date directly affects the lives of those living with FASD and their families. These insights gave rise to questions about policy decision-making which has been guided by the technical authority of medical and research elites. Funding has continually been allocated to preferred programs and projects with the aim of building an evidence base which then, in turn, substantiates further funding. While such research is valid, there has been no consequence for the alcohol industry, and a very poor investment in support services for families.

As a case study, FASD has the characteristics of a wicked problem – a problem which is the consequence of a much bigger problem, and with multiple stakeholders emerging over time with differing frames of reference, a lack of consensus in either defining the problem or in identifying possible solutions, and struggles between stakeholders for domination of their preferred position. In their seminal paper on wicked problems, Rittel and Webber (1973, pp. 155–169) identified ten characteristics of wicked problems against which FASD can be assessed.

1. There is no definitive formulation of a wicked problem.
2. Wicked problems have no 'stopping rule'. i.e. no definitive solution.
3. Solutions to wicked problems are not true-or-false, but good-or-bad.
4. There is no immediate and no ultimate test of a solution to a wicked problem.
5. Every (attempted) solution to a wicked problem is a one-shot operation; the results cannot be readily undone, and there is not opportunity to learn by trial-and-error.
6. Wicked problems do not have an enumerable (or an exhaustively describable) set of potential solutions, nor is there a well described set of permissible operations that may be incorporated into the plan.
7. Every wicked problem is essentially unique.
8. Every wicked problem can be considered a symptom of another problem.
9. The existence of a discrepancy representing a wicked problem can be explained in numerous ways.
10. The planner has no 'right to be wrong', i.e. there is no public tolerance of experiments that fail.

FASD is a unique problem in that it has insidious characteristics. The actions of others (alcohol use in pregnancy) directly impact on the fetus, exposing the individual to the risk of lifelong disabilities. In addition, FASD has other dimensions of harm, which can be distinguished by separating those directly affected from those secondarily affected. Each group has a different frame of reference from which they interpret and understand the problem and determine possible solutions. FASD is a spectrum of neurodevelopmental conditions which have physical, psychosocial, emotional and/or economic consequences, for the individual with the condition, for their parents and family, for their community, and for society. The cause of FASD is alcohol, so FASD is part of a much larger problem.

All alcohol-exposed pregnancies are at risk, as no known minimum amount of alcohol has been determined as safe in pregnancy. Prevention essentially involves a universal and cautionary message to all women of childbearing age, as no-one knows which pregnancy might be vulnerable. This makes FASD a whole-of-population concern.¹ A first consideration is those pregnant women who are low- or high-risk alcohol consumers, those who abstain once pregnancy is confirmed, and those who for multiple reasons, including personal choice, are unable or unwilling to cease alcohol use. Some of these women have unplanned pregnancies, so many fetuses are exposed to alcohol in the first trimester. A second consideration is those individuals born with the effects of fetal alcohol exposure.

¹ The following section is based on knowledge acquired by the author of this research from work experience.

This population group is largely ‘invisible’, and it is often the case that their behaviour, a consequence of neurological impairment and developmental delay, will not be diagnosed. A third consideration is the parents and families. Parents may be separated according to status: birth, adoptive, foster or kinship. How the different population groups are understood in terms of need, or of the approach required to manage the problem, depends on prevention.

The prevention of FASD can be best described on three levels: primary (raising public awareness); secondary (targeting those at risk); and early intervention (targeting those for whom a problem already exists). Primary prevention currently includes campaigns and information disseminated by multiple mechanisms; but the content of the messages delivered is contentious.

Linking with wicked problem characteristics, consideration must be given to cultural sensitivities, must be consistent in message, and focus on the teratogenic risk of alcohol use. Messages should be non-judgmental and promote thoughtful consideration on a personal level. In Australia, various groups deliver these messages, which are often underpinned by Guideline 4 of the Australian National Alcohol Guidelines (2009).²

In secondary prevention strategies for fetal alcohol exposure and/or FASD, which group/s to target is a core decision. In respect to alcohol use in pregnancy, screening and motivational interviewing are often understood as the optimal mechanisms for delivering education. Most women will cease alcohol use upon confirmation of pregnancy; however, as with primary prevention strategies, certain groups are perceived to be at higher risk of continuing to drink. Often the focus of prevention will be young women, Aboriginal women or other marginalised women: which opens it to charges of being discriminatory. Male parents are now also attracting attention, as the science of epigenetics considers why some fetuses are particularly vulnerable to *in utero* exposure to alcohol.

In early intervention, the focus is on women who continue to consume alcohol during pregnancy, particularly those who use alcohol in high-risk patterns of consumption. A secondary focus is on the children borne to this group of women, generally determined by facial and other typical manifestations of prenatal exposure to alcohol. Little is done outside research in Australia to address the complex issues that often take precedence for potential parents over heeding messages to abstain from alcohol – including poverty, violence, poor housing, unemployment, and intergenerational alcohol misuse.

² Australian National Alcohol Guidelines (2009) are accessible at <https://www.nhmrc.gov.au/health-topics/alcohol-guidelines/>

The original demands made to government by parents in the 1990s asked for informed discussion, for cross-system collaboration; for knowledge- and skills-informed diagnosis for the appropriate screening of women; for prevention through public and professional awareness campaigns; and for labelling on alcohol beverages. Some of these are currently progressing; others have not yet been met. Policy solutions have emphasised building an Australian evidence base, despite accepting the ‘harmonising’ of the Australian FASD diagnostic tool with the Canadian guidelines in early 2016. International research and resource information informs current Australian literature and the available online resources for families.

The FASD ‘problem’ was first raised by foster and adoptive parents. They had limited success in attracting policymakers’ attention, so sought to engage with people of influence in the hope that this could be improved. Although public policy agenda-building on FASD by the Commonwealth government was slow for a decade (2000–2010), a few medical professionals and researchers have since then been invested with technical authority status. In recent times the problem has achieved policy issue status, with a national plan and allocated funding to pursue certain objectives. A recent position statement by the Australian Medical Association reveals the policy focus is medical in construct (Australian Medical Association, 2016).³

To date, clinical and community based research has focused on marginalised communities and women known to be high-risk drinkers in pregnancy who are easy to access. Policy solutions aimed at building an evidence base have failed to account for lived experience, so those living with FASD and their families, whose issues largely manifest within a social construct, must rely on those with government authority to represent their interests in the health policy framework.

At the Commonwealth policy level, in the lead-up to the 2016 Federal election the caretaker government announced \$10.5 million would be invested in building on the ‘significant achievements’ of the Commonwealth National FASD Action Plan to reduce the impact of Fetal Alcohol Spectrum Disorders 2013–14 to 2016–17. These ‘achievements’ are not as significant as suggested, and fall very short of the 19 recommendations detailed in *Hidden Harm* (Standing Committee on Social Policy and Legal Affairs 2012). The priorities of the first version of the Plan are consistent and targeted public information on the risk of alcohol use in pregnancy; focused attention on women with alcohol

³ Point 11: Government commitment to ongoing funding and support for the outcomes of the Commonwealth Action Plan, including the establishment of a National FASD Hub, the continuance of the National FASD Technical Network and National FASD Clinical Network, and development of a National FASD Register and Implementation and Evaluation of the Australian Guide to the Diagnosis of FASD, and treatment services for alcohol misuse in pregnancy.

dependency issues; diagnosis and post diagnostic management, prevention and management of FASD in Aboriginal and socially disadvantaged communities, and national co-ordination, research and workforce development. In the second version, there is an anticipated roll-out of a national FASD clinical network and an information hub to provide up-to-date information, to support diagnosis and undertake data collection. Support for communities in which FASD prevalence is determined to be high was proposed, modelling the primary prevention success of the Fitzroy Crossing Marulu Lilliwana Project where use of alcohol in pregnancy plummeted from 60 to 18 per cent in 2015 (Australian Government 2015). Neither the second version of the Plan nor any updates on the achievements of the first have been made publicly available on the Commonwealth government website since June 2015.

In addition to the National FASD Technical Network, an Expert Committee for the Implementation of the Diagnostic Instrument is operating and the FASD Clinical Network, which was established in 2015, is currently seeking funding to investigate the efficacy of evidence-based interventions to improve executive functioning in children diagnosed with FASD. In 2015 the Banksia Hill Juvenile Justice Screening project in Western Australia began to screen all juveniles in detention for FASD with funding secured through a grant from the National Health and Medical Research Council. This project was launched at about the same time that the results of the Fitzroy Valley prevalence study revealed a staggering 1 in 8 children diagnosed with Fetal Alcohol Syndrome (Fitzpatrick et al. 2015, pp. 450–457), among the highest in the world. A second study has yet to be launched in the Cherbourg, Queensland community.

In 2016 four FASD Clinics are operational in Australia, one at Westmead Hospital, Sydney and a second on the Gold Coast (Gold Coast Health), in Queensland. The FASTrack Clinic is located in Perth, Western Australia, and Patches Clinic operates in Perth and the remote communities of northern Western Australia. These are paediatric centres, and diagnosis for adolescents and adults is not available unless assessed by a clinician with the skills for such a diagnosis. Voluntary support groups are currently accessible in Perth, Western Australia; Alice Springs, Northern Territory; the Gold Coast and Cairns in Queensland; and Hobart, Tasmania. Two of these groups meet face to face, and the remainder are only accessible online.

The Australian Diagnostic Instrument was launched in April 2016⁴ to harmonise with the revised Canadian FASD Diagnostic Guidelines (Cook et al. 2015). The advancement of FASD-related services is seemingly reliant on the take-up of the new diagnostic instrument by clinicians and allied

⁴ The Australian FASD Diagnostic Instrument can be accessed at <http://alcoholpregnancy.telethonkids.org.au/australian-fasd-diagnostic-instrument/>

health workers. Diagnosis, particularly in respect to the neurodevelopmental part of the fetal alcohol spectrum, depends on interdisciplinary collaboration and is more likely to be achievable in urban locations. Ongoing support for individuals, their families and supporters requires access to appropriately skilled personnel across multiple service delivery sectors – health, education, employment, mental health, economic support, disability, justice, child protection, child and family services and out of home care. FASD is a problem for those already living with it and those who will be affected in the future.

1.1. RESEARCH AIMS, OBJECTIVES AND KEY QUESTIONS

This research aims to better understand the influences on the progression of FASD as a complex and intractable problem from the original demands for problem attention through the public policy process to reach a formal and/or public agenda. Reliant on archival records concerning the progression of FASD as a problem in three countries, and qualitative data from interviews which introduce the perceptions of various stakeholders, the objective is to explore how the problem has been managed as a public policy.

Within this overall aim, the research anticipates responding to several questions. First, what makes FASD such an intractable problem when science has delivered evidence of alcohol toxicity and adverse fetal outcomes? Secondly, as an advanced developed country, why has there been such resistance to tackling the problem of FASD prevention in Australia, and is this the case in other similarly developed nations? Thirdly, as a problem, is FASD intractable because of problem complexity or is it influenced by the contest among multiple stakeholders to have their preferred position on problem definition or solution taken up by policymakers?

There are continual demands by parents and families for change. Most support that is offered comes from outside government, with little or no funding, although FASD is usually unrecognised in individuals and therefore impacts on the effectiveness and efficiencies of government jurisdictions and systems in service delivery – clinical and mental health, allied health, justice, child and family services (child protection, out of home care), employment, economic dependence, education and disability. Cross-sector collaboration is required. The perceptions and experiences of individuals, parents and families must be accommodated. The alcohol industry must be included as a major stakeholder. The research proposes that the continued application of traditional linear or authoritative policy solutions for a complex problem like FASD has achieved little other than to perpetuate problem wickedness, rather than to find resolutions. FASD as a wicked problem requires collaboration, as there is no alternative to deal effectively with such an intractable problem (Head & Alford 2015, p. 725). It is to this conundrum that this research now turns.

1.2. CHAPTER OUTLINE

Every story has a beginning, a middle and an end, and FASD is a story worthy of telling. Following the Introduction, Chapter 2 details the mixed method approach used to conduct interviews and gather data; the process used to construct the stories of the problem in three countries using archival records, and the position of the researcher as participant/observer.

An overview of the problem of FASD is presented in Chapter 3. The early story unfolds with a brief historical background leading to the ‘rediscovery’ of an old problem in 1973. An overview of the problem in the four decades since then is provided, and the impact this problem has on the lives of those who live with FASD across their lifespan is explored. The chapter details the evolution of diagnostic criteria and ends with a description of some of the more contemporary challenges. Some of the major events concerning FASD provide evidence of how attempts to resolve this wicked problem have unfolded over the decades from 1973 to 2013. Themes emerge from the archival records on the importance of advocacy; the pervasive use and social acceptance of alcohol use, in which FASD is embedded as a harmful consequence; gender and the discretionary practice of targeting some girls, some women and some mothers as key determinants of problem resolution; the attention on First Nation communities as sites for FASD research and problem solution; and the evidence needed to convince governments to better fund prevention.

In Chapter 4, the research turns to an examination of different types of problem, with particular attention to exploring the elements of wicked problems and, particularly in contemporary times, some of the approaches taken to dealing with them. A conceptual model of public policy agenda building is introduced to describe the progress of a wicked problem from the point at which an initiator group raises its demands to attract the attention of policy decision-makers. If the progress of demands is stymied, proponent groups engage other more influential status groups to draw attention to their demands; however, this risks changes to the original demands. More dominant groups have different definitions of the problem and preferred solutions.

In Chapters 5, 6 and 7 the stories of unfolding events in the United States, Canada and Australia highlight the importance of the knowledge transferred from the United States to Canada and then to Australia. The events in each of the stories in each chapter are drawn from archival records and are separated by major themes covering the four decades from the 1970s.

In Chapter 8, qualitative data collected from participant observations are presented explicitly and organised according to the major themes which emerge; then in Chapter 9, a comparative analysis is presented to highlight the critical variables in both the archival and the qualitative data. Some conclusions are made about possible solutions for the future.

CHAPTER 2 RESEARCH METHODS

The research uses a multiple method framework drawing on archival records to construct stories of the same problem in the three countries and qualitative data collected from semi-structured interviews with participants from those same countries. The author's professional experience working in the area of Fetal Alcohol Spectrum Disorder informs an understanding of the problem as complex and intractable. The initial research proposal was based on the view that the United States and Canada were more advanced in responding to the problem and, therefore, some insights on problem definition and progress towards solutions might be gleaned. Australia shares commonality with the United States and Canada on many socio-political levels – a history of conquest and settlement by Britain, federal and responsible parliamentary government, and broadly similar economic structures. There are, however, important differences, such as constitutional arrangements and the ethnic division between English- and French-speaking Canadians.

The chapter follows a 'disciplined-configurative' approach which describes and analyses cases in terms of theoretically relevant general variables. This permits, as George (1979) emphasises, focused comparison with other cases and the culmination of findings. The advantage of using a 'most similar case study' approach is that where the problem is one of accounting for specific differences, the selection of cases for analysis that possess many similarities in terms of relevant variables makes clearer the identification of factors which do differ; these may therefore be considered primary candidates for investigation as explanatory variables. Finally, and indisputably, this research can be understood as a 'plausibility probe' in that it presents some 'provisional' findings in anticipation that any conclusions may open space for future research (George 1979, p. 58).

2.1. LITERATURE REVIEW

The construction of the stories of FASD over time in each of the three countries draws from archival records or the author's own collection of printed documents (reports, books, research papers) acquired during employment or voluntary work in the FASD area. Some sources of information come from the author's recorded notes (conference and meeting participation) or emails. Electronic searches were made using the Google search engine with the following topics: alcohol use in pregnancy; women and alcohol use in pregnancy; research on alcohol use in pregnancy; FASD; FASD in the United States, FASD in Canada; FASD in Australia. Databases consulted included the National Institute on Alcohol Abuse and Alcoholism (hereafter NIAAA); the Center for Disease Control (hereafter CDC); the Canadian Centre for Substance Abuse (hereafter CCSA); the Public Health Association of Canada (hereafter PHAC); government health portfolios; and The University of Tasmania Library: ProQuest databases.

2.2. SEMI-STRUCTURED INTERVIEWS

Central to this research is the building of stories of the same problem in three systems – the United States, Canada and Australia. This was achieved by consulting archival records in the three countries and complemented by qualitative data collected from semi-structured interviews conducted with thirty-two stakeholders. From these two sources, information was coded to determine any similarities or differences in how the problem has been managed. Not only do the stories shed light on the scope of the problem and validate concern about the issue: they also offer a glimpse into FASD public policy and the various influences which have shaped FASD prevention efforts over four decades. The events narrated in the stories highlight similarities in the attempts to reduce the incidence of alcohol use in pregnancy and the prevalence of FASD, and also some differences in the sources of influence over the problem's development. There is also strong evidence from participant observations that the definition of the problem and possible solutions are contested.

2.2.1. PARTICIPANTS

As stated, qualitative data was collected from semi-structured interviews undertaken by the author. Participants' professional practice and/or direct experiential knowledge of the problem from working with individuals who live with FASD, in their respective fields of interest and their respective countries, bring richness to the study.

Thirty-two participants were interviewed, 12 from the United States and 10 each from Canada and Australia. Participants were coded according to country (United States 01; Canada 02; and Australia 03); other codes reflect their primary role (refer Table 1 below). Almost one third of participants identified as researchers, eight as parents and three as medical practitioners.

Prior to interview, prospective interviewees were provided with an information sheet (Appendix 1) and a set of questions (see below), and were asked to complete and sign a consent form to confirm the participant's agreement to proceed with the interview (Appendix 2). Participants were offered the choice of writing their responses or undertaking a telephone interview; five asked for a direct interview. In all cases, the notes that I recorded during the interview were provided to the participant for any amendment or additional comments, and confirmation.

Table 1 Participant list

Role	United States	Canada	Australia
behavioural scientist	BS0101	-	-
medical practitioner	MD0102 MD0107	-	MD0326
researcher	RS0103 RS0105 RS0108 RS0110	RS0214 RS0217	RS0324 RS0327 RS0330 RS0331
child health	CH0104	-	-
health promotion	HP0106	-	-
birth or adoptive parent	BP0109	AP0213 AP0216 BP0220	BP0323 BP0325 AP0328 AP0332
non-government organisation administrator	NG0111	-	-
educator/trainer	ET0112	ET0221	-
legal/educator	-	LP0219	-
government policy	-	GP0215	-
service provider	-	SP0218 SP0222	SP0329

2.2.2. INTERVIEW QUESTIONS

The set of ten questions was designed to elicit responses on the sources of positive and negative influences on the progress of the problem, the effectiveness and efficacy of solutions tried over time, and preferred solutions for the future.

1. Can you tell me how you first became involved in the prevention of FASD?
2. What factor/s do you believe have been most influential in developing the issue?
3. What factor/s do you believe have been the biggest impediment or challenge in the development of this issue?
4. Who do you think has been most important in bringing the matter of FASD to the attention of policymakers and the public?
5. Is there a person or entity who you can think of whose support for the prevention of FASD will be essential in the future?
6. Conversely, is there a person or entity whose opposition would seemingly be almost impossible to overcome?
7. What, if anything, do you think keeps government interested in the prevention of FASD and doing something about the issue in your country?
8. What, if anything, do you think slows down or gets in the way of FASD prevention policy development in your country?

9. Who has held or holds leadership as the authoritative spokesperson on aspects of this issue?
What is it that they are able to say that attracts attention to the issue?
10. What do you think will be the new FASD prevention policy directions/initiatives in the future?

The outcome of Question 1 was intended to act as a prompt in establishing rapport (Minichiello et al. 1995, p. 79). Questions 2, 4, 5 and 9 were designed to elicit factors of positive influence on the progress of the problem in each country, while questions 3, 6 and 8 were designed to gain information on any impediments to the problem. Questions 7 and 10 aimed to gather an understanding of the perceptions of participants on what influences policy attention, and new policy initiatives in the future. Once the interview notes were confirmed, the data was recorded using participant coding (Table 1, above) for each country and each question. This process was followed by a second round in which the collated data was organised in accordance with overarching themes. This process enabled comparison of the responses across the three countries.

2.2.3. RESEARCHER AS PARTICIPANT-OBSERVER

My work in FASD over the past decade has been a significant motivation for developing this research project. I have worked in prevention and advocacy, supporting individuals and families who live with FASD, and have delivered national education and training on FASD and related topics like women and alcohol use and misuse. In addition, I have held and continue to hold membership in many FASD interest groups in Australia; this is what motivated this research.

Access to key networks and a privileged position enabled me to gain an inside view of the unfolding story of FASD, particularly in Australia, so that this research has been conducted as both participant and observer. Gold (1958, p. 217-223), as cited in Cohen et al. (2006), surmises that the researcher as participant observer provides access ‘to a setting by virtue of having a natural and non-research reason for being part of the setting so that in effect, as observers, they are part of the group being studied’.

A declared personal bias is acknowledged, as is a level of caution in remaining reflective of the interpersonal stake held in this dual role. As both researcher and informant, there is awareness that there is ‘a field relationship’; the risk of over-identification is reduced through a one-off interview in the case of this research (Gold 1958, pp. 220–221). My own work has been shaped by Minichiello et al.’s (1995, p. 10) observation that ‘the thoughts, perceptions and feelings experienced by informants [facilitate access to] the motives, meanings, actions and reactions of people’ on a subject (in this case FASD).

2.2.4. QUALITATIVE CONTENT ANALYSIS

As previously stated, 32 participants were interviewed, at which time a saturation point was reached for the amount of data which could be managed. All participants had high levels of knowledge or expertise in respect to FASD, which validated a low cut-off point for the number of interviews required (Bonde 2013, p. 4). In interviewing participants on their subjective experience, their number was guided by the proposal that little new information emerges from interview transcripts 'after you have interviewed 20 or so people' (Green & Thorogood 2004). Even so, the interviews resulted in more than 280 responses, and often these included thoughts on a range of issues.

The qualitative data from the interviews was organised through a system of content analysis described as appropriate to transcripts 'of semi-structured interviews in which the unit of analysis is a paragraph' (Gläser & Laudel 2013). Each participant was assigned a de-identifier code by applying 01, 02 or 03 according to country, then letters representing the main area of interest in FASD and an assigned number between 1 and 32 for each participant (Table 1). Each transcribed interview was entered against the corresponding participant de-identifier code and then reduced, to summarise each participant's response to each question.

Pre-identified categories provided a beginning point to search for patterns in the information and the prior assumptions were made explicit (Gläser & Laudel 2013). This process reduces the openness of the first step – creating the categories – but introduces openness in the second step – applying the categories to the empirical material (Gläser & Laudel 2013).

New information which fell outside the pre-identified headings was organised under additional categories and the data were then aggregated and integrated. Any contradictory information was included under the heading it related to (refer, Appendix 4). The summarised interview data and the organising of data within pre-identified or emerging categories was a methodical step-by-step process aiming for openness (Kohlbacher 2006).

2.3. RESEARCH LIMITATIONS

This research is qualitative, and as such is an exploration of events and ideas which might add to understanding the nature of social issues and how these may be dealt with. The complexity of social issues means the application of scientific rigour in demonstrating exactness in defining either a wicked problem or its solutions will at best offer possibilities rather than set procedures.

A key characteristic of a wicked problem is that it is either a consequence of a much bigger problem or is interconnected with other multiple problems. As a wicked problem, FASD is a harmful consequence of alcohol use; and at this time scientific evidence links FASD only with maternal alcohol use. For this

reason, the social construction of gender and therefore of power disparities and notions of mothering are accepted as powerful forces which underscore much of the policy approach and inform the frames of reference which emerge in the archival records and qualitative data. The reasons women continue using alcohol, aware of the risks in pregnancy, cannot be adequately addressed in this research although Badry (2007) in her hermeneutic research and writing style on the lived experiences of birth mothers has contributed to greater empathy and understanding.

It is worthwhile noting that the events described in the stories of fetal alcohol exposure and FASD are far from exhaustive. Selection was based on those incidents that emerged as key turning points in community advocacy or government policy, or as a flow-on from one subject to another. For example, research on the topic of fetal alcohol exposure might lead to research on women's use of alcohol in pregnancy or FASD diagnosis, as the history of each country was compiled. Often one document cited sources of information which led on to related topics.

Adding to information on the subject matter is literature and resources accumulated over time in the course of professional work: hard copy, electronic and online. The historical collection of records gathered by Peggy Seo Oba (2006) was invaluable. The selected time frame for this research is 1973 to 2013, chosen to reflect the year in which the seminal paper on fetal anomalies was published in *The Lancet* (Jones et al. 1973, 'Pattern of malformation in offspring of chronic alcoholic mothers') and the following four decades through to 2013. In the chapter on Australia, a section is included to provide an overview of major related events from 2014 to 2016.

The scope of the research was limited to FASD as a wicked problem with a particular focus on the three levels of prevention, to identify factors contributing to problem complexity and exploring the space between stakeholder demands and government policy responses. Major themes emerged within the social construct of gender and cultural bias in research, and alcohol as a socially and culturally acceptable behaviour. These are overarching issues which could not adequately be addressed in the scope of this research.

One of the key limitations in this research was the number of interviews with participants which could be practically undertaken. Not all stakeholder frames of reference were accommodated (for example, alcohol industry representatives or Aboriginal peoples in different communities across all three countries). The number of participants was limited to ten or twelve: United States = 12; Canada = 10; Australia = 10. Travel to the United States and Canada provided an opportunity to meet four participants and resulted in introductions to two other interested parties. Australians interviewed were known to me in my professional capacity as network contacts in respect to the stake they hold in the problem of FASD.

Every attempt was made to interview participants across similar fields of interest. As can be seen in Table 1, the Australian participants did not include a representative of a non-government organisation, service provider or government policy person. The list of Canadians interviewed reflects the absence of medical practitioner. One such person was approached but declined to be interviewed. Further, there was no Canadian interviewed who was engaged specifically in research. However, it should be pointed out that some participants had diverse interest areas. For example, all but one of the parents interviewed had other roles in research, service delivery or Aboriginal health promotion, but identified their parenting role as their primary interest area.

A standout limitation is the overlap between emerging themes. The complexity of the problem of FASD resulted in a high yield of data, and the diversity in the range of responses cannot be underestimated. It was also the case that questions designed to elicit information on positive influences on the progress of the problem resulted in responses about barriers rather than about what might have been helpful. It was also the case that reflections on subjects like the diagnosis of children living with FASD could not be easily separated from the subject of women at risk of alcohol use in pregnancy.

CHAPTER 3 CONCEPTUAL FRAMEWORK

Indisputably, FASD is an intractable problem. But why is ‘the FASD problem’ seemingly without resolution, and why there has been such policy resistance? The focus of this chapter is to describe different types of problems and then to give focus to those problems which are complex and more resistant to traditional approaches before exploring some of the considerations in dealing with them. In the second part of the chapter, a conceptual model of public policy agenda-building is presented as a framework to examine the progress of a wicked problem as it moves through various phases, beginning with making an initial set of demands. Public policy agenda-building considers the power and influence of attention groups as these emerge during the phases of specification and engagement; and how the problem as an issue (or not) is managed before gaining issue attention (or not); and then is presented as policy on the formal and public agendas.

3.1. DEALING WITH INTRACTABLE PROBLEMS

Wicked problems, as social issues, are managed within the public policy arena and decision-making is determined by ‘the preferences and agenda setting of political leaders, legislators, lobbyists, and stakeholders, mediated through media communication and public opinion’ (Head & Alford 2015, p. 711). The ten characteristics of wicked problems (Rittel & Webber (1973, pp. 155–169) have been mentioned previously in this thesis, as has an overview from the author’s professional experience of the complexities of FASD for consideration in meeting these ten characteristics. Overwhelmingly, defining and resolving FASD as a wicked problem is dependent on the contests which occur among stakeholders as they push for their preferred definition of the problem and its possible solutions. Others have simplified or added to the list of characteristics over time. For example, Williams and van’t Hof (2016, p. 7) merged some characteristics of wicked problems and reduced the number to six main elements:

- (i) every wicked problem is novel or unique;
- (ii) there is no stopping rule; you can’t hit the pause button;
- (iii) the problem is not understood until the formulation of the solution;
- (iv) wicked problems are complex, they have no single cause, no single effect and have no given alternative solution;
- (v) every wicked solution is a ‘one shot operation’; there is no off-the-peg ‘best practice’ answer; and
- (vi) solutions are not right or wrong, but they may be better or worse.

Head and Alford (2015, p. 711) argue of this that there are degrees of wickedness; and at a more extreme level of complexity, Levin et al. (2012, p. 123) claim that some wicked problems should be named 'super wicked'. Super wicked problems have the added characteristic of a definitive time frame for resolution and the persons trying to solve the problem are also causing it. Further, Levin et al. claim the 'central authority' needed to manage a 'super wicked' problem 'is weak or non-existent' and that policy solutions irrationally 'discount the future'. The result is tragic, they argue, and arises from governing institutions having policy positions that are short-term even when the implications of this are catastrophic, while longer-term collective benefits are overlooked (p. 124).

3.1.1. TYPES OF PROBLEMS: SIMPLE, COMPLEX OR WICKED?

Problems have been described as simple, complex and wicked (Roberts 2000); or puzzling, complex and wicked (Ackoff 1974); or messes and social messes (Horn & Weber 2007, p. 3). At their most complex, wicked problems display degrees of wickedness (Head & Alford 2015, p. 712) or as Levin et al. (2012, p. 123) propose, at their most complex may be called super wicked problems. Distinguishing one type of problem from another can therefore be visualised on a continuum of increasing complexity, from simple to super wicked.

In addition to escalating complexity, problems can also be categorised according to the level of consensus on definition and/or solution, and the consequences of any decision-making (McConnell 2016, p. 1). Therefore, problems may be defined by the level of contestability embedded in their handling by those with assumed or invested technical authority or decision-making power. Another distinguishing feature across different problem types emerges in the literature as the level of collaboration required (or not) in resolving problem types.

Labelled as Type 1 problems (Roberts 2000, p. 1) or puzzles (Ackoff 1974), simple or tame problems are managed by experts who generate policy solutions on a linear pathway which, as such, might be referred to as 'taming' solutions. A simple problem will attract a low level of conflict, is of a type that is standardised and routine, with solutions grounded in certainty, prior experience and knowledge of what will work. In policy making, solutions are said to be most often responsive to the citizenry that the government serves (Head & Alford 2015, p. 712). In contrast, consensus in defining a problem caused by conflict among stakeholders over possible solutions indicates a complex or Type 2 problem. Depending on how this problem is understood, issues emerge about how it can be solved.

Collaboration is required to achieve consensus among stakeholders as to the best solution, and once this is achieved the problem may revert to being understood as simple. If there is a high level of conflict over definitions both of a problem and of its possible solutions, then a Type 3 or wicked problem is indicated (Roberts 2000, p. 1).

3.1.2. APPROACHES TO WICKED PROBLEM RESOLUTION

Wicked problems are social problems, and people construct meanings about them according to their different values and beliefs. Rittel and Webber argue that judgments differ in line with interests, values and ‘ideological predilections’, and that people will therefore ‘choose those explanations which are most plausible to them’ (1973, p. 161). As Roberts notes, wicked problems are ‘ambiguous, fluid, complex, political, and frustrating as hell’, and are symptomatic of other problems with frequently unforeseen consequences (2000, p. 2). Interpretation ‘comes down to the values of those involved’, and the struggle for preferred positioning is ‘evolving at the same time policy makers are trying to address the problem’ (Rittel & Webber 1973, pp. 155–169).

Wicked problems are unique and symptomatic of a much larger ‘super wicked’ problem, and therefore there is no definitive solution. Nor is there a test for a solution; and in the absence of agreement on the best course of resolving the problem, the result could be good or bad. Wicked problems are ‘incomprehensible and resistant to solution’ (Head & Alford 2015, p. 712) – yet time and urgency are factors in decision-making. As such, dealing with social issues is often reliant ‘on political judgements rather than scientific certitudes’ (p. 714), which leaves the process open to impediments created by ‘the working mechanisms of the public sector’ (p. 733). However, policy that makes appeals to scientific expertise ‘will seldom generate acceptable solutions’, especially when scientific and technical authority has been ‘deeply compromised in the modern context of social media and values-based political debate’ (p. 717). Stakeholders attach their own meanings in the attempt to find solutions to wicked problems.

In the contestable space which results as different groups struggle to dominate, the practical challenge that must be overcome is problem fragmentation and failure (Conkin 2007, p. 4). This challenge is not helped by practices in which problems and solutions are shaped by traditional and accepted institutional policy-making approaches and only part is informed by scientific evidence (Head & Alford 2015, p. 717). Problem fragmentation ‘manifests itself in tensions between program-based subcultures, competing policy priorities, and, at worst, turf wars within and between agencies’ (p. 719), creating consequences for those affected by other parts of the problem that were never considered.

Wicked problems are ‘complex, interdependent issues that lack a clear problem definition and involve the conflicting perspectives of multiple stakeholders’ (Huggins & Hilvert 2013, p. 8) and defy solution (Roberts 2000, p. 1). They have multiple meanings, reflective of the diversity of stakeholders who are invested in a problem and its resolution. This means that alternative approaches require a primary consideration of people, their unique understanding and perspectives. The challenge of these ‘competing frameworks’ (Roberts 2000, p. 5) is to draw together an integrated and informed approach

considerate of all knowledges, skills and experiences. When not attended to, conflict can erupt in the jostle for power over preferred descriptions and/or solutions. A network approach to the resolution of wicked problems (p. 1) attends to the resolution ‘process’ rather than separately responding to fragmented parts of a wicked problem, a consequence of conflict inherent in the divergent value and belief systems of participants. There is movement towards a better understanding of ‘wicked problems’ and the acceptance of multiple frames of reference for how the problem is defined and understood ‘in terms of potential solutions within respective and varied contexts’ (p. 13).

A second consideration is the importance of collaboration, which increases exponentially with problem complexity. The process of championing alternative solutions and competing to frame ‘the problem’ to fit a preferred solution (Roberts 2000, p. 1) and then match the solution with a preferred problem definition, depends on the underlying struggle about ‘which group is right and which should have its ends served’ (Rittel & Webber, 1973, p. 169). With wicked problems there are winners and there are losers.

Creating a strategic framework should not be expected to be easy; and as experts see the world differently, very different definitions of a problem and solutions are likely. As wicked problems are socially defined, people intuitively construct meaning, and this means differences are the norm. Each variation of meaning is believed ‘to hold truth and if differences are given focus, participants speak ‘past one another instead of with one another’ (Roberts 2000, p. 13). Houghton (2015, p. 1) uses the notion of ‘framing’ to describe the unique ways individuals have of perceiving reality, which informs problem definition and the interpretation of problem causation. These alternative representations of the same problem are the basis of the struggle among stakeholders to find solutions; and ‘framing contests explain why some ideas triumph over others’ (p. 4).

As described earlier, three types of problems are identified by Roberts (2000, p. 1): simple, complex and wicked. Roberts also defines three types of strategies emerge in dealing with wicked problems: authoritative, collaborative and competitive (pp. 3–4). Depending on the amount of conflict present in dealing with a wicked problem, the strategy applied can recast the problem differently, as depicted in Figure 1 (below).

When the concentration of power is placed in the hands of a few expert stakeholders, authoritative strategies are used (Roberts 2000, pp. 3–4). These strategies are ‘taming’, in that there is less conflict over core issues and stakeholders tend to yield to more professional and specialised experts who are assumed to have relevant skills not usually found among the general public. A smaller number of expert stakeholders means less complexity, conflict, time and resources; it means that things can get things done. However, experts ‘can be wrong – wrong about the problem and wrong about the solution’ (p. 4), as they identify solutions from within their professional or experiential stream.

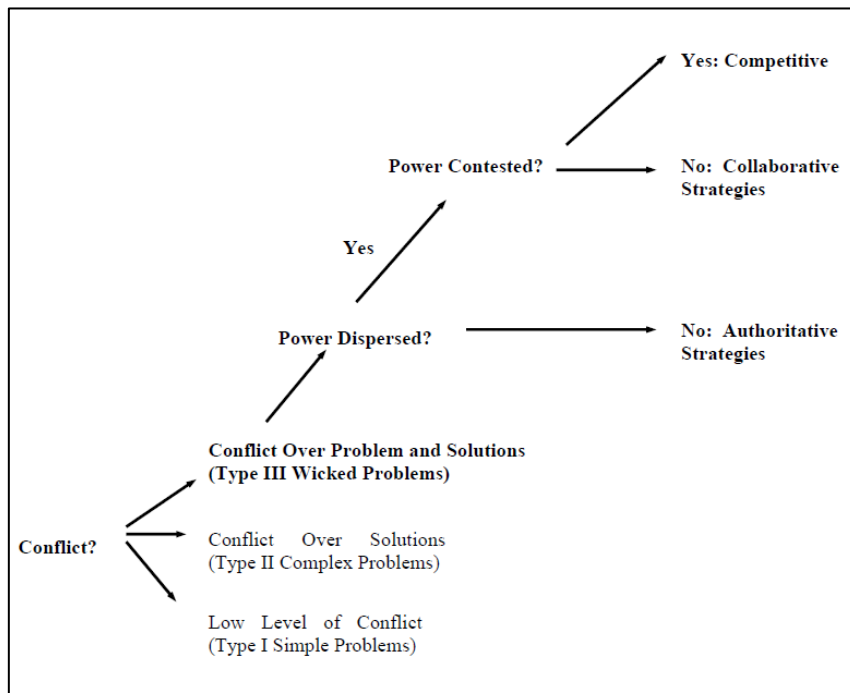


Figure 1 Coping strategies to deal with wicked problems. Source: Roberts 2000, p. 3

The wicked problem may be, by default, fragmented; and the part of the problem which reflects a preferred definition and solution may gain more response, with consequences for those whose stake in the problem is denied attention. Roberts (2000, p. 15) suggests that participants take care in attempting to ‘tame’ wicked problems by handing them over to experts from some centre of power for definition and solution, because when no-one is in control of a wicked problem, it is unlikely that experts and leaders will be able to act unilaterally to define problem and solutions. The use of authoritative strategies to deal with wicked problems may distance citizens from the important issues (p. 5).

Competitive strategies are used when power is dispersed but not contested; without consensus on the definition of a problem or solution, competition among stakeholders is great (Roberts 2000, p. 6). Winning is the aim in the search for concentrated power to dominate other stakeholders in the promotion of a preferred definition and solution. Tactics can include aligning with others to build supportive power bases. If successful, those with most power can ‘tame’ the problem by conversion to authoritative strategies, so avoiding ongoing conflict (p. 5). In the extreme, conflict among stakeholders can lead to violence, huge financial burdens and stalemates as exemplified in the early indecision of some parties to join the fight against AIDS, indecision which ultimately cost lives (p. 6).

Collaborative strategies result when there is conflict over both wicked problem definition and solution. There are advantages to collaboration in cost and risk sharing, organisational efficiency and output. Considering the multiple frames of reference of many people increases costs, with more meetings

required to achieve synergy and negotiate for consensus. Roberts (2000, p. 7) points out that many working in bureaucracies do not have collaboration skills and that acquiring these skills takes time.

While a single 'frame' might expedite the resolution of a simple problem, the diversity of values across the different groups of individuals who are stakeholders in wicked problem decision-making and resolution can lead to a stalemate, as 'what satisfies one may be abhorrent to another or what is a problem solution for one generates a different problem for another' (Rittel & Webber 1973, p. 169). Bringing opposing frames together to solve complex problems creates conflict, and in the struggle one 'frame' will dominate. The concept of 're-framing' is posited as 'opposing alternatives' (Houghton 2015, p. 4) and useful in the construction of a new frame that can become 'the template for future action' (p. 2).

In one case study of an Australian workplace, Houghton (2015) describes an initial set of solutions to improve efficiency, learning, communication and an improved supply chain as reliant on technology to drive more efficient practices (p. 9). The development of technology to address a problem that was understood only in part or in an underdeveloped failed to solve the matter, and led to workers engaging to reframe the problem from a social perspective. The workers did not share a reciprocal understanding of other work roles, but could accommodate a variety of meaningful, alternative views to the better manage the problem.

In the case of more complex problems, resolution invariably requires increased collaboration as sub-groups with a common interest organise to negotiate for a preferred solution or to a suite of partial solutions. When power is dispersed but uncontested in complex problems, collaborative strategies can be used (Roberts 2000, p. 4). Domination of one group over another may occur, but if the predominant group lacks the power to achieve resolution, progress on accomplishing issues of importance is hindered, authoritarian strategies may be adopted to tame the problem, and the matter is 'put in the hands of a few with authority to define the problem and find a solution' (Roberts 2000, pp. 4–5). If power 'is dispersed and contested', competitive strategies may be used. Central to these are 'a search for power' and the use of tactics and ethical compromise, within accepted moral parameters, to build a dominant base of influence over defining the problem and its potential solutions (Roberts 2000, pp. 4–5).

Wicked problems are complicated by psychosocially sensitive elements and characterised by limited acknowledgement of wide stakeholder interests. Some issues have 'moral, psychological, religious or cultural dimensions' and are described as 'unspeakable' problems (Grant-Smith & Osborne 2016, p. 46). Further, the authors propose such issues are not discussed in 'a rational and emotional -free way that conventional planning demands and can become obscured or inadequately acknowledged in planning processes' (Grant-Smith & Osborne 2016, p. 46). This might be considered as differing in

process to the example provided by Roberts (2000): in this case, various issues of concern are identified and allotted to smaller 'self-managed' groups 'to develop strategies and action plans' based on consensus. Participants are asked 'to rank issues in order of their personal priorities' and in the process 'to seek common ground rather than dwell on differences' and 'keep comments off the record and not for attribution' (Roberts 2000, p. 11). Roberts notes that participants are not discouraged from holding these separate discussions in smaller group meetings held elsewhere.

In respect to complex social issues, Grant-Smith and Osborne propose that 'unspeakables' are in themselves wicked problems which 'elicit powerful negative emotional responses', and not discussing these phenomena acts to deny 'social and political entitlements'. Revealing such frames of reference are argued to 'help explain resistance and reticence' to engaging in collaborative strategies (2015, p. 46).

Co-operation leading to an emphasis on collaboration is a key element in dealing with wicked problems, and involves coordinated action by governments, non-government agencies, private businesses and individuals, particularly if behavioural change is required as part of the solution. Collaboration provides access to a more encompassing set of knowledges and skills, and in turn encourages wider thinking about the interaction of these 'variables, options and linkages' (Head & Alford 2015, pp. 727–28). Such approaches negate reliance on 'experts' and authoritative strategies by drawing together '*expert* knowledge' and 'situational knowledge based on social or institutional location' (Head & Alford 2015, pp. 727–28). In effect, involving 'non-experts' may create a wider contextual landscape of the problem and provide access to the perceptions of what impact any solution might have on the public whose lives are directly affected. Successful collaboration is not a given, and power struggles may still emerge as 'gaming behavior' to perpetuate problem wickedness (Head & Alford 2015, p. 727). Nevertheless, collaboration promotes more regular communication and offers opportunities for divergent interest groups to discover areas of common ground.

If the element of truth is respected, then what is heard helps individuals understand the scope of the problem and possible solutions. Mutual trust and reciprocity of commitment in the collaborative process can be challenging in public policy-making environments subject to shifts in political, financial and resourcing conditions. Head and Alford (2015, p. 722-723) consider that greater consideration of the diverse 'variables, options, and linkages' which underpin the different 'frames of reference' participants represent is dependent on leadership approaches. Rather than ignoring stakeholder differences, new leadership in dealing with wicked problems will help to find different ways to take responsibility in building a 'shared narrative' to accommodate 'the implications of value preferences' and deal with the conflicts.

Beyond the facilitator's set guidelines, a 'community of interest' event may lead to 'a complex adaptive system with its own rules of behavior, reflective of behavior and self-directed in interactions based on what it [is] learning' (Roberts 2000, p. 15). It requires trust in the process, 'to get on with it rather than wait until everything is in place' and participants' 'willingness to make a leap of faith – to work together with integrity and trust in the collective effort without guarantees' (p. 15). This is a 'come as you are' event with uncertainty about what will happen and how.

Head and Alford (2007) endorse the value of collaborative approaches in exploring the role of leaders to bring 'a degree of coherence and mindfulness, if not control, on its workings' (p. 728). They suggest leaders can promote adaptations (p. 730) to tackle challenges, as do Heifetz et al. (2009, p. 14). Such leadership skills can be 'displayed by people across an organisation, not only by those in senior positions or management roles' (Briggs, 2007, p. 14). New leadership approaches can complement collaboration.

This is what might be described as a transformational leadership model, which focuses on a single corporate leader who sets a vision and encourages others to pursue it, with direction and in what Heifetz (1994, p. 103) calls a 'holding environment'. A second model is adaptive leadership, focused on 'bringing forth knowledge that is beyond the compass of a leader acting alone' (Head & Alford 2015, p. 729–730) and in mobilising people 'to tackle tough challenges and thrive' (Heifetz et al. 2009, p. 14). Collaborative leadership is the interaction of leadership with collaboration, as the name suggests. The leadership skills of communication, influence and trust-building are intermingled with collaborative skills operating outside a hierarchy, eliciting contributions from participants not recognised as authorities. In respect to government administration and systems, Head and Alford (2015) suggest developing a collaborative leadership style requires organisational flexibility 'to assemble and reassemble project teams as problems emerge, progress, and come to some sort of resolution' (p. 731). Team membership which is representative of cross system interests acknowledges the complexity of wicked problems; consideration of the determined purpose; or cost sharing based on shared outcomes (p. 732).

Public problem solving, despite its name, is often separate from ordinary citizens; and when engagement with stakeholders from outside government systems does occur, these representatives of other groups must be 'authentic appointments' (Lukensmeyer, 2012). The inclusion of such external stakeholders can draw on collaborative leadership models to assemble project teams that in turn, draw on a wealth of life experiences and as proposed by Mertens (2015, p.5), there is a need for 'qualitative relationships' which focus on addressing any distrust if they are to achieve more than measure the scope of the problem.

Conklin (2007, p. 4) argues that it is the ‘coherent action, not final solution’ that is important, plus the facilitation of a negotiated ‘shared understanding and shared meaning about the problem and its possible solution’. The notion that participants fall into collaboration (Roberts 2000, p. 12) to find common ground is valid, but a greater emphasis has emerged in the last decade on the importance of attending to different ‘frames of reference’ (Houghton 2015) and addressing some proscribed subject areas (Grant-Smith & Osbourne 2016). As Saul (1992, p. 2) argues, ‘Change can only come through what will seem at first to be outrageous, statements, provocation and a stubborn refusal to accept the smooth, calm, controlling formulae of conventional wisdom’.

3.2. A CONCEPTUAL MODEL OF PUBLIC POLICY AGENDA BUILDING

Wicked problems are policy problems too, and proposed and deliberately augmented strategies to deal with them are indicated by the progress (or not) of the problem onto formal and public policy agendas. An insightful conceptual model of public policy agenda building by Cobb, Ross and Ross (1976) is useful in understanding how problem types and authoritative, competitive and collaborative strategies are used to manage wicked problems. Three patterns of agenda-building are organised according to four phases:

- the *outside initiative* pattern describes those situations where problems are raised by groups outside government to (a) attract policymakers’ attention, and (b) achieve issue status on the formal and public agendas;
- the *mobilisation* pattern describes situations where problems are proposed by leaders from within government in anticipation of public support for successful implementation;
- the *inside initiated* pattern is for those policy proposals which emanate from within or near government decision-makers, often influenced by stakeholder groups. Within each pattern are four phases of development: initiation, specification, expansion and entrance.

The three patterns and the phases within each are briefly detailed in Table 2 (below), but it should be noted that differences in agenda-building patterns occur across polities, and the effects of the different ‘social, structural and political positions’ of the participating groups are important to success or failure (Cobb et al. 1976, p. 127). These authors suggest that higher success rates are related to greater social homogeneity, a greater number of potential agendas, and a reduced likelihood of redistribution of material resources. They also propose links between the policy successes of grievances initiated by large groups in more egalitarian societies who ‘represent lower status interests’ and suggest that even in the absence of limited material resources, an ‘outside initiative’ pattern is more likely in egalitarian societies.

Table 2 Patterns of public policy agenda building

Pattern	Phase	Description	
Outside initiative	Initiation	Individuals or groups outside government express grievances to attract policymakers' attention and achieve issue status.	
	Specification	Initiator group may not be specialised in articulating the grievance. Members may share grievances but may also come from more than one source. Group may not be united in the articulation of their demands.	
	Expansion	Initiator group engage with new groups and risks losing control of the issue to more powerful groups. Emotive symbols are used to connect with the general public. The initiator group seeks to engage with likeminded groups rather than attract new supportive groups.	Identification group – small group, strongly connected with initiator group and position.
			Attention groups – issue-focused rather than loyal to initiator group; mobilise quickly around controversy.
			Attentive public – small minority, informed and interested in public issues. May not be united and yet be interested in both sides of the controversy.
			General public – last to be involved, interest short lived, level of interest crucial to forcing item onto formal agenda.
Entrance	The shift from the public agenda to the formal agenda for serious consideration of an issue that concerns a large number of people.		
Mobilisation	Initiation	Problems are proposed by leaders from within government in anticipation of public support for successful implementation.	
	Specification	Announcement contains few details but there are expectations of public support.	
	Expansion	Issue is government policy as soon as announced. Requires public support.	Identification group – political leaders. Opposition can mean failure.
			Attention groups – the link between political leaders and mass public through public statements of support; may include leaders from issue-relevant specialist organisations.
Entrance	From formal to public agenda.		
Inside initiative	Initiation	Proposals emanate from within or near government decision-makers, often influenced by stakeholder groups. More homogeneous, closer aligned in values and beliefs.	Identification group – government colleagues.
			Attention groups – selective groups are influential on decision makers, stressing the urgency and importance of the issue and and pressing acceptance by decision makers.
			General public – unaware of issue.
	Specification	Proposal articulates details. Fear of public misunderstanding of technical details.	
	Expansion	Limited. Focus is on influential groups, not on public. Does not seek to expand issue in the public agenda. A private decision within government.	
	Entrance	Formal agenda status achieved. Not on public agenda. Sanctions may be used against opponents, favours for those who cooperate.	

Source: Cobb et al. 1976, pp. 128–136

Attentive public groups are defined as small minorities of people who are informed and interested in public issues generally, and hold strong views but may not be united. This increases the likelihood that the membership of the attentive public group may align with ‘both sides of the controversy’ (Cobb et al. 1976, p. 129). The general public group is described as having fleeting involvement with an issue and the last group to become involved; but it is always crucial in applying pressure on decision-makers to move the issue onto the formal agenda. In the other direction, those with concentrated wealth and status in a society and initiator groups who represent upper-status interests are likely to use an inside access pattern. Regions and smaller communities are said to be more ‘mobilisable’ in agenda conflicts when they are economically and ethnically homogeneous, as these are necessary for successful expansion in the mobilisation pattern.

The success of an issue in reaching the formal agenda is dependent on the ‘strategies used to prevent the success of initiating groups’ and the roles of various sources of influence in determining which issues attract the ‘serious attention’ of policymakers (Cobb et al. 1976, p. 126). A problem raised by a small initiator group to the domain of a larger public group must move through the stages of specification and expansion. Specification involves the articulation and structuring of demands and requires particular skills, particularly when the problem is complex. Expansion to other, often high-profile, attention groups can assist in the specification phase, particularly when attention groups are able to articulate the technical details of the problem and gain the ear of government. After this the issue must be expanded sufficiently to attract policymakers’ attention before it can reach the formal agenda. All this is a simplification of a complicated process: Cobb et al. (1976, p. 137) advise that it is worth bearing in mind that ‘most occurrences of agenda building will certainly be more complex, combining models as well as levels of agendas’.

In the following three sections, an overview of each model is presented with attention to the four stages of agenda-building and the strategies used by proponents and opponents to promote or limit success. These strategies are often consistent across the models, but crucial differences at three points in agenda-building are apparent. Firstly, different strategies can affect the desired outcome, either advancing or hindering the issue from reaching public awareness; and any problem raised by a small initiator group to the domain of a larger public group must move through the stages of specification and expansion. Secondly, expansion to other, often high-profile, attention groups can assist during the specification phase. Thirdly, the issue must be expanded sufficiently to attract policymakers’ attention before it can enter the formal agenda, which is limited to those policies which are accepted for serious consideration: there are many issues that fail to attract such attention. The public agenda is defined as issues that have ‘widespread’ attention or problem awareness, ‘require action’, and from the perception of the concerned public group ought to be a concern of ‘some governmental unit’ (Cobb et al. 1976, pp. 126–130).

Four different types of expansion groups occur within these three patterns of agenda building: identification, attention, attentive public and general public groups (Cobb et al. 1976, p. 128). While identification groups are likely to be large and to identify with and support the original participants and their position on an issue, attention groups are attracted by the public issues inherent in the conflict, rather than on the originating concern. The last two groups arise from the mass public and may seek out controversy, which is not always in the interests of the identification group. Dealing with complex problems requires the articulation of technical details and specific skills in the structuring of demands, characteristics which may or may not be present among initiator group participants. During the specification phase, the degree of group cohesion or divisiveness can add or detract from the initiator groups' ability to maintain the objectives of the original grievance, and there is the risk that control will shift from the initiator group as 'more powerful groups enter ... and the original participants grow less important' (Cobb et al. 1976, p. 128). This is called issue expansion; and there is a risk of issue redefinition or 'the substitution of one issue for another, usually a more specific issue being redefined into a more general one', as Schattschneider (1960, p.71) puts it.

Following the announcement of a new policy, specification is limited to a series of proposals to other key government leaders and decision-makers, bearing in mind the new policy is competing for priority status with many other issues, often across different portfolios. To avoid any possible objection from opponent groups, the first stage of expansion is limited to only those groups where support is most likely, and which can be rewarded with reciprocal benefits. Such a strategy reflects the use of elitist power bases to the benefit of the policymakers, as these selected engaged expansion group participants often represent a congruence of values, norms and mores. Deliberate expansion strategies based on selective identification may have the effect of strengthening the policymakers' position, suggesting urgency in terms of policy priority while denying the public the opportunity to bring oppositional pressure. Likewise, the process can be stalled if the subject arouses public opposition and the government may refuse to take action.

Securing mass public appeal to mobilise the movement of an issue from the formal to the public agenda is dependent on securing constituent compliance. When success may be endangered by predictable public opposition, the risk can be reduced through a carefully structured expansion phase that keeps the issue off both the formal and public agendas and the public remains largely unaware and uninformed.

3.2.1. OUTSIDE INITIATIVE MODEL

According to the outside initiative model a grievance or concern is expressed in a general way by organised or semi-structured groups outside government; the source of initiation separates the outside initiative model from the other two 'inside government'-initiated models. In this pattern, issues or

grievances raised by groups outside government must not only attract the attention of decision makers to reach the formal agenda but must expand sufficiently to raise public awareness sufficient to place it on the public agenda. Cobb et al. suggest that while some non-government groups form for the specific purpose of raising a concern and may or not be organised, other groups may or may not be already known in the community and may or may not have had 'previous experience and success in articulating interests'. The initiator group's ability to articulate specific demands may or may not be a specialised role, and unity in the expression of demands may or may not be characteristic. There may be diversity in the demands being made, and whether these are representative of society will depend on the experience of group members. A group's ability to articulate, structure and redefine demands marks the specification phase, which can be crucial in creating 'sufficient pressure or interest to attract the attention of decision makers' (1976, p. 128).

The elements of group cohesion or divisiveness can add to or detract from the initiator group's control during the specification phase, and their ability to maintain the objectives of their original grievance. Success in this phase requires the use of different strategies to gain policymakers' attention, and the engagement of new groups may introduce differing interests on the issue. While wider involvement is crucial to successful agenda-building, it also brings the risk of a loss of control by the initiator group as 'more powerful groups enter ... and the original participants grow less important' (Cobb et al. 1976, p. 128). Critical in societies with a policy context of competing demands, the authors suggest expansion stage strategies in the outside initiative model can be aimed at other small interest groups or the general public, to attain public agenda status and to pressure governments to consider the issue being raised. One expansion strategy is to form small groups specific to the distinct role of issue promotion; but while such groups offer the advantage of non-association with other issues, there can be a disadvantage in the absence of prior knowledge and sources of influence.

In the final stage of agenda-building, the problem is translated to an issue that has moved from the public agenda to the formal agenda and is determined to require 'formal consideration' (Cobb et al. 1976, p. 129). The authors note that the transition period from public to formal agenda is neither automatic nor speedy. In industrialised countries, the process can be stalled if the subject arouses public opposition and governments refuse to take action. In this case, the decision not to act is a non-decision, preventing an issue from entering the formal agenda.

3.2.2. MOBILISATION MODEL

In the second pattern (the mobilisation model), a position on the formal agenda occurs 'almost automatically', given that the issue is initiated by political leaders or those with close access to the nexus of policy decision-making. However, even if the issue gains automatic placement on the formal agenda this does not mean that it will automatically be implemented without public support. In some

instances, automatic formal agenda status may mark the policy decision's 'end result'. Indicative of the initiator's power and dominance, this pattern of agenda-building 'is often found in countries where great social distance between leaders and followers is expressed' (Cobb et al. 1976, p. 127).

While the initiators in this pattern might have the material resources necessary to implement a new policy, this is moderated by the specific characteristics of the issue. The new program needs to reflect traditional values and norms but be sufficiently different to existing policy to attract the public; in addition, the new policy needs to consider what matters to people, as reflected in smaller local agendas. Communication is essential; and according to Cobb et al. (1976, p. 134), organisational structure must be such that regional interests can be satisfied various communication mechanisms that bridge the gap 'between formal announcement and public awareness'.

Gathering political party support (the identification group) is probably initiated within government prior to the public announcement of the policy's placement on the formal agenda. Inter-government negotiation and lobbying often occurs without public knowledge, but once formal agenda status is in place there is some surety that the public will come to hear of the policy. Public announcements on new policies are often vague in detail but strong on information about what is required from the public. Securing mass public appeal is necessary to mobilise the movement of the issue from the formal to the public agenda.

Successful expansion occurs in one of two ways. Strategically selected and engaged attention groups are essential to the expansion phase, used to articulate support for new government policy initiatives and attract the attention and support of the public. The identification group of leaders is usually already established, but it may now be expanded to include more government members and lower government officials who indicate their support. Through expansion strategies outside government circles, attention groups may be co-opted from groups of specialized elites who act as links between government and public. These elites hold regional influence and opinion, which can be utilised to engage the general public.

Co-opting the support of attention groups and attentive public groups has risks. The attentive public have existing networks within the mass public, and their opinions are often persuasive. Poor strategic choices in expansion can mobilise opposition to a new policy and result in failed implementation.

3.2.3. INSIDE INITIATIVE MODEL

While the mobilisation model requires the support and compliance of the public for successful implementation, the third pattern of agenda building (the inside initiative model) occurs most frequently in 'societies characterized by high concentration of wealth and status' (Cobb et al. 1976, p. 137). The inside government-initiated agenda-building pattern occurs in situations where the initiators

seek 'automatic' status on neither the formal nor the public agenda. Although the issue originates inside government or from groups close to political decision-makers, its successful passage and implementation is dependent on select expansion to certain influential groups for necessary support, to the exclusion of the general public. These influential groups offer the least risk of wanting changes to the policy proposal; and if the new policy is in their interest, they may use their position to influence certain government leaders or decision makers to initiate the new policy as 'brokers' on their behalf; in this way their exposure as initiators remains relatively safe and silent (Cobb et al. 1976).

In the first model of agenda-building (outside initiative model), expansion works to promote awareness and apply pressure on government through public participation. In the second model (mobilisation model), expansion is limited to discrete public groups who mobilise support. It is still a necessary strategy to move the issue from the formal to the public agenda: when success may be compromised by predictable public opposition, this risk can be reduced through a carefully structured expansion phase to keep the issue off both agendas. Such private decision-making within government circles is characteristic of the inside initiated model. Cobb et al. (1973) suggest the formal agenda is limited to those policies which are accepted for serious consideration: many other issues fail to attract such attention.

3.3. SUMMARY

The characteristics of wicked problems includes approaches to their resolution. The effects of different 'social, structural and political positions' (Cobb et al. 1976, p. 127) of participating stakeholders can lead to the implementation of 'taming' strategies to address wicked problems by those who exert the greatest influence. This research uses conceptual patterns of public policy agenda building to understand the role of influences in the progress of FASD as an issue and to determine if these processes contribute to problem wickedness. In advancing public policy agenda building, a shift from an 'outside initiative' pattern to an 'inside initiative' pattern emerges as governments strive to limit the impact and scope of a problem on the public agenda. An analysis of the interview data reveals little on achievements to date other than a narrow focus on problem solution. There is frustration for some in convincing others about what needs to happen for change to occur. The working mechanisms of government in managing wicked problems is a vast impediment to addressing, in the case of FASD, the needs of individuals and families who live with the consequences of policy decision-making based on 'scientific reports and new research' (Head & Alford 2015, p. 722) and which fail to acknowledge diverse narratives and lived experiences.

The interconnection of wicked problem theory with the patterns of agenda building draws attention to the way in which demands made by groups outside government may be managed at a public policy decision-making level through a shift to an inside initiated pattern and from competitive to

authoritative strategies. The closer public policy agenda-building 'fits' with an inside-initiated pattern of agenda building, the more likely it is that authoritative strategies will be the preferred choice of policymakers. In this way, public policy decision makers maintain control in containing the problem and, suppressing the full scope of the problem from the public agenda.

In the following chapter, an overview of the problem of FASD is presented, followed by chapters on each of three countries: the United States, Canada and Australia. The selected key events in respect to public policy on FASD provide evidence of the complexity and intractability of FASD, particularly as groups engage in mobilising their preferred solutions. They also indicate some similarities and differences in the strategies used to 'tame' the problem.

CHAPTER 4 FETAL ALCOHOL SPECTRUM DISORDER

It has been over four decades since dysmorphologists David Smith and Ken Jones of the University of Washington, USA, published their research and findings on maternal alcohol consumption. They found causality between similar patterns of physical anomalies among eight children of an unrelated group of alcoholic mothers (Smith & Jones 1973). Since then, the science of fetal alcohol exposure has rapidly advanced, from that early association of fetal anomalies with high maternal alcohol use to the recognition that a much lower threshold of alcohol exposure may cause fetal harm on a continuum from subtle to significant.

The problem of FASD was evident in the mid-eighteenth century, when the availability of cheap gin resulted in what became known as the ‘gin epidemic’ in Great Britain’s major industrial centres, and the social problems it caused led to calls for government regulation on maternal drinking by certain mothers (Sanders 2009, p. 289). William Hogarth (1697–1764) produced artwork titled ‘Gin Lane’ which portrayed the impoverishment of the time. In the United States, Benjamin Rush published a pamphlet, ‘Ardent Spirits’, in 1785 and challenged the notion ‘that alcohol was good for you’ paving the way to understanding alcoholism as a disease (Blocker et al. 2003). A physician named Thomas Trotter published his ‘Essay on Drunkenness’ in 1804, and it was claimed to be the first ever published book on alcohol dependence and its treatment (Edwards 2012).

In the 1870s Canadians experienced an economic depression but alcohol manufacturing flourished, and the impact of alcohol consumption became the subject of prohibition campaigns by groups of women. The first documented use of drugs by women appeared in the eighteenth century, at a time when patented medicines were commonly taken for women’s health issues like menstrual symptoms and anxiety. These medicines often contained alcohol, and dependence among women users became common. The commonality of its use did not equate with the moral condemnation it attracted. The escalation in the consumption of laudanum in the nineteenth century, for example, was a consequence of medical prescription, as prescribed medicines were more acceptable to society than patented formulas. The sale of alcohol continued to flourish despite prohibition legislation, and illegal drinking establishments were scattered across Canada.

In Australia by the 1890s, the temperance movement had some 70,000 members. In a 1920s referendum, one in three voters expressed their support for a prohibition on alcohol in their state (Fitzgerald & Jordan 2009, p. 101), as ‘according to temperance advocates, many women developed alcoholism from constantly imbibing medically prescribed spirits’: this tended to happen in solitary settings, and evidence began to emerge showing that drinking was ‘not a working-class issue’ (p.99). Nor was it lost on feminist writers that ‘the temperance movement was a sex war’ (Lake 1987, p. 98).

At the same time, a British study of female drunkenness among inmates of a Liverpool prison found stillbirth rates to be 2½ times higher than among a ‘sober’ peer group (Sullivan & Scholar 1899). Sullivan in the same year examined the adverse fetal implications of inebriety by studying 600 children born to alcoholic mothers; he determined that effects in the offspring were uncorrelated with either paternal alcohol use or generational familial alcohol use. Moreover, when drinking by the mothers of these affected children was coercively controlled, their subsequent children were found to be normal (Sanders 1975, p. 290).

The temperance movement gained momentum in the early 1900s, mobilised by moral and religious attitudes and fuelled by lobbyists Rush and Trotter (Warner et al. 1975), and linkages were proposed connecting maternal conduct and alcohol consumption with ‘weak, feeble and distempered children and increased stillbirth and infant mortality’ (Fox 2005). In Canada by 1920–21 prohibition was losing ground, with British Columbia, Manitoba and Saskatchewan revoking legislation and making alcohol available through government. According to Sanders (1975, p. 290) in this period temperance ended. Anti-prohibitionists countered its claims: scientists determined that much of the research on alcoholism was ‘moralistic and unscientific’, and research on prenatal exposure to alcohol waned as the emerging social sciences eventually led to an increased understanding of the influential determinants of poverty and child abuse on child health and wellbeing.

The effects of alcohol continued to attract scientific interest, and papers were published in periodicals such as the *British Journal of Inebriety* published between 1876 and 1914 (Blocker et al. 2003). Research also gained momentum in France. Nicloux (1900) documented the effect of alcohol in animal and human breast milk on offspring, and Ladraque (1901) observed weak and poor development in the infant children of alcoholic mothers. The impact might have already been experienced across many generations in many societies (Fetal Alcohol Drug Unit 2001; Golden 2005, p. 16–34), an argument supported by Sanders (2009) in a review of the historical literature. Streissguth (2003, p. 36–52) also details a long history of the awareness of the adverse outcomes of fetal alcohol exposure, when discussing documented reports on the children born to alcoholic mothers.

In a 1910 Scottish study, maternal alcoholism was linked to the short stature of hundreds of school children (Pearson & Elderton 1910). According to Streissguth (2003, p. 36), Sullivan’s demonstration of the risks of fetal alcohol exposure in the late 1800s were ‘apparently largely unheeded’, and even though the research supported abstinence, this and other findings were used selectively for moral, religious and political purposes by the Temperance movement, rather than for their scientific value.

As in Canada earlier, Prohibition was repealed in the United States (in 1933) and temperance was described as ‘losing moral ground’ (Streissguth 2003, p. 36). Drinking became ‘fashionable’, and per capita alcohol consumption increased steadily, more than doubling in the next decade. Streissguth

cites the work of Fretz (1931, p. 145), who highlighted the period from 1930 to the end of the Second World War as a time when research into the effect of alcohol on the fetus was ‘accepted by most authors, doubted by some, and denied by a few’. Doubt was revived a decade later by Haggard and Jellinek (1942), who associated infants born to alcoholics who displayed ‘feeble-mindedness, mental disorder, idiocy, and epilepsy’ were the product of ‘poor stock’ and social upheaval (cited in Streissguth 2003, p. 36).

A proliferation of experimental animal studies in the United States in the 1950s (Papara–Nicholson and Telford 1957) and in Romania (Sandor 1968; Sandor & Amels 1971) began the study of teratology: teratogenic substances or conditions that cause birth defects. Alcohol, as a teratogenic substance, was found to cause ‘death, malformations, growth deficiency, and functional deficits’ (Streissguth 2003, p. 56). An accepted principle of teratology advises that ‘the greater the dose, the larger the anticipated response’ (Streissguth 2003, p. 56–57); so doses, timing and patterns of alcohol intake during pregnancy; the blood alcohol levels of mother and fetus; and fetal metabolism and elimination (about half the adult rate) were all considered to have relative adverse fetal impacts.

In more recent times, the understanding of alcohol as threatening to normal foetal development began in earnest after the devastating impact of the prescription drug Thalidomide. This event challenged the prevailing ideology that the uterus was *sacro sanctorum*, and that birth defects were ‘genetic’ and reflected parental ‘flaws’. (International Birth Defects Information Systems 2006; Thalidomide Victims Association of Canada 2006). Dr Christy Ulleland, a paediatric resident at King County Hospital in Seattle, used medical records to identify eight infants who displayed growth deficiencies at birth and later developmental delays (Ulleland 1972; Ulleland et al. 1970). David Smith and Kenneth Jones, dysmorphologists at the University of Washington, examined the children from Ulleland’s study along with other children known to be born to ‘alcoholic mothers’, and by 1973 had constructed a ‘careful description of the constellation of physical features; growth deficiency; and intellectual, motor, and adaptive behavior impairments’:

These observations indicate that infants of alcoholic mothers are at high risk for pre- and post-natal growth and developmental failure, and suggest that greater attention should be given to alcoholic women during the child bearing years. (Streissguth 1997, p. 38)

The characteristics of the children in the Lemoine study were ‘stunningly similar’ to those in the Washington study, and a series of articles from the University of Washington on Fetal Alcohol Syndrome spurred worldwide interest as clinicians recognised and reported similar findings (Streissguth 1997, p. 40). The clinical findings replicated those from the previous century: stillbirths, infant mortality and growth delays were consequences of alcohol use in pregnancy. The significant advance from earlier research was the scientific evidence of alcohol as causal to the characteristic

facial features that are the observable and measurable sign of fetal alcohol exposure. The findings were published in the international medical journal *Lancet*, and the condition was named ‘fetal alcohol syndrome’ (Jones et al. 1973).

Within two years, Warner and Rosett (1975) reviewed the literature on FAS and called the findings a ‘rediscovery of the effects of alcohol on the developing fetus’ (cited in Sanders 2009, p. 288). The research agenda was advanced by Smith, Jones and Streissguth in 1974 through a case/comparison study drawn from a national database on the causes of neurological impairments in children, particularly focusing on the children of mothers noted as affected by alcoholism. The study was reported in Jones et al. (1974, p. 1076) and the findings indicated higher than normal numbers of these children suffered from lower IQ, greater intellectual impairment, and more perinatal and post-natal mortality. These findings were described by the US Department of Health, Education & Welfare (1979, p. 42) as having ‘dramatically sharpened the focus on the relationship between ethanol intake by the pregnant woman and the health of the infant’.

Within a six year period, 618 individuals with FAS had been identified internationally; by 1980 it was estimated that the impact of prenatal exposure to alcohol directly affected 1.9 per 1000 Americans (Smith 1979, p. 165–172). FAS was determined to be a problem affecting individuals wherever alcohol was consumed (Abel & Sokol 1987, p. 51–79), and by the first decade of the 21st century fetal alcohol exposure was reported as the major preventable cause of mental retardation in the developed world (Kyskan & Moore 2005, p. 153–165).

The Seattle Longitudinal Prospective Study on Alcohol and Pregnancy began at the Fetal Alcohol Drug Unit the same year with the aim of following up and assessing approximately 500 individuals with prenatal alcohol exposure. The study sought to examine what happened in the lives of these people ‘from birth to adulthood’ (Astley 2005, p. 4), and the results indicated ‘a surprising rate of premature death, early school dropout, and major adjustment problems’, with half of the group noted to have IQs below 70. (Streissguth et al. 1985). This older population group who had been exposed to fetal alcohol did not qualify for special education, and the findings indicated their ‘facial features had dissipated’ which resolved a question about why a limited number of adolescents had been diagnosed (Streissguth 1997, p. 44). This outcome set the stage for expanding the definition of FAS and developing a more comprehensive understanding of the cognitive, developmental and behavioural components across the full spectrum of adverse effects that might be suffered from fetal alcohol, and the impacts it had across a lifespan.

In a response to the scientific evidence available at the close of the 1970s, Dr Judith Hall, a geneticist, is reported in a Progress Report by the Bureau of Alcohol, Tobacco and Firearms as advising on the migration of neurons and cell development across all three trimesters of pregnancy and arguing that

the evidence from the available data was that there was a risk to fetal brain development from maternal alcohol consumption at any time of the pregnancy. Behaviour, brain abnormalities and psychosocial illnesses including hyperactivity were suggested to be outcomes for which evidence was not yet available. Hall recommended that these conditions attract long-term follow-up, particularly in children born to mothers who used alcohol at moderate levels or in 'binge' patterns; she pointed to the risks of drinking 'perhaps even very small amounts or only during critical periods' (Hall 1979, p. 12).

Individual case descriptions of children with FAS were published by Streissguth, Herman and Smith (1978) and Clarren and Smith (1978) to clarify the toxic nature of alcohol, the association of Fetal Alcohol Syndrome with maternal alcoholism, the effect of maternal misuse of other drugs, and other possible environmental factors that might increase adverse effects in those afflicted with FAS. This early work engaged the National Institute on Alcohol Abuse and Alcoholism (NIAAA); the US Bureau of Alcohol, Tobacco and Firearms and the United States Surgeon General. As of now, the relative wickedness of the problem is emerging only in respect to mounting evidence that fetal alcohol exposure may not just be limited to the children of women using alcohol at very high levels. The policy response has been twofold: (i) a federal mandate through seed funding to intervene in female alcohol abuse during pregnancy to prevent FAS granted to the FADU for a 'pregnancy and health study' (hereafter PHP) through NIAAA (1979 to 1980); and (ii) approaching the US Surgeon General to consider his issuing a health warning.

The PHP study reported on by Little et al. (1984) and Streissguth (1997, p. 251) marked the US government's earliest investment in prevention research. The former focused on primary prevention through public education and included a key slogan, public service announcements, media coverage of public events, brochures, posters and a hotline operated by five trained volunteers. By the close of the 1970s, 6,000 professionals had accessed some level of training on the risks of fetal alcohol exposure and 7000 brochures and professional information packs had been distributed. Public awareness was growing in Washington State with one in every 44 pregnant women making contact with the University of Washington's 24-hour hotline established from the initial seed funding (Streissguth 1997, p. 252). The National Institute for Alcohol Abuse and Alcoholism (NIAAA) organised the first international conference on FAS in 1980 in Seattle, convened by Ann Streissguth and David W Smith from the University of Washington (Astley 2005). Such was the weight of the medical research at the time that by 1981 the US Surgeon General recommended women not consume alcohol during pregnancy or when planning a pregnancy; by 1989 legislation had been enacted by Congress to require warning labels on all alcohol beverage containers (Streissguth & Kanter 1997, p. 27).

Medical knowledge of fetal alcohol exposure and risk transferred from North America to a section of the health research community in Australia. This is evidenced by four research papers published in the late 1970s and 1980s (Collins & Turner 1978; Lipson et al. 1983; Turner 1979; Walpole & Hockey

1980). Joseph Correy, a Tasmanian obstetrician, had begun collecting data on alcohol use in pregnancy in Tasmania prior to the 1980s (Correy 2012). Walpole and Hockey's (1980) paper on the implications of FAS on family and society noted that 34 children had been diagnosed with FAS in Australia, a claim they proposed was the outcome of 'heavy or heavy episodic consumption of alcohol in pregnancy'. Eighteen per cent of the children were identified 'as Aboriginal' (Bower 2012). Later, Ashwell and Zhang (1994; 1996) published findings from animal studies relative to prenatal alcohol exposure and the impact of alcohol on optic nerve and forebrain hypoplasia, and advised of the need for prevention.

In 1983 the Indian Health Service (IHS) in the United States allocated funding for the FAS Follow-up Project, which achieved 'a ten-year follow up of the first eleven children ... diagnosed with FAS, and the follow-up of larger groups of adolescents and adults with FAS & FAE' (Streissguth 2003, p. 256). The study aimed to determine problems encountered by those living with FASD, and by the close of the decade education for the prevention of FAS had been delivered to 2,000 trainers in 92 Indian Health Service Units for dissemination to Native Americans and Alaskan Natives (Streissguth 2003, p. 256). A news article in 1989 reported that as many as 25 per cent of children on Native American reservations in the Plains area could be affected by FAS, a problem developing over 'the past 20 to 30 years' (*Boston Globe* 1989). Workers from a Sioux reservation estimated that half the infants and young children there presented with symptoms consistent with FAS, and attributed this to the habit of early settlers to trade alcohol for land, starting the tendency toward the development of alcoholism in later generations. The editorial called for immediate federal government intervention through the establishment of alcohol treatment programs and offering economic assistance to offset the huge unemployment crisis on reservations (*Boston Globe* 1989). Warning labels on bottles, estimates of the prevalence of fetal alcohol-exposed children, and information on the plight of First Nation communities was not enough: public awareness relied on hearing people with status articulate the scope of the problem, showing the full extent of the impact of FASD on individuals, families and communities.

Through its focus on research, the United States developed case descriptions of those living with FASD and their relationship to different patterns of maternal alcohol use during pregnancy; this led to building the capacity of service providers working with families at risk of FAS in those marginalised communities where prevalence was considered high. The emphasis on science to deliver undisputable evidence on alcohol toxicity to fetal development was critical to convince the public of the risk and would not dissipate. One of the ways to achieve this was to focus on diagnosis.

4.1. FASD: A LONG ROAD TO DIAGNOSIS

Fetal Alcohol Syndrome has observable physical signs which are measurable even immediately post-birth. A constellation of three hallmark features of the condition are specified for a diagnosis of FAS: dysmorphic facial anomalies, small growth for age, and central nervous system impairment. A presentation of partial FAS may also be diagnosed when physical signs are less dominant, but the diagnosis still requires two or more facial abnormalities from a list which includes a flattened midface, a smooth philtrum (crease between lip and nose), and a thin upper lip. Small eye openings are common, with wider spacing than normal between the eyes. The facial dysmorphology which typically makes the Syndrome noticeable in the post-birth period and infancy can dissipate with age, minimising the opportunity of a diagnosis if it went undetected in early life (Greenbaum et al. 2002). FAS and partial FAS (hereafter pFAS) do not require confirmation of maternal alcohol use. A longitudinal study published in 1978 (Hanson et al. 1978, p. 457, 460) demonstrated that some of the characteristics of FAS and pFAS were present in children born to mothers ‘who drank moderately or socially’, further support for the theory that the effects occur on a spectrum, linked with the doses and timing of alcohol exposure.

Diagnosis within the neurodevelopmental/ neurobehavioural part of FAS is dependent on assessment of functional ability, such as speech and language, executive functioning, memory and learning. The untrained medical practitioner is more likely to miss these and diagnose the patient as having other conditions – possibly attention deficit, autism or another behavioural disorder. It is not always the case with Alcohol Related Neurodevelopmental Disorder (hereafter ARND) that intellectual disability is assessed in the neurodevelopmental/neurobehavioural part of the spectrum; however, the primary impact on the structures of the brain means individuals can experience mild to significant impairment in brain function.

Executive functioning may be impaired, impacting on the capacity to plan, sequence and follow through. Speech and language impairments can affect information processing so that the person has difficulty understanding concepts and instructions. This may be masked by the ability to articulate or repeat words, and may lead to incorrect or unfair labels being applied, based on presenting behaviours. Short-term memory may also be compromised, and will affect learning: developmental delay (dysmaturity) is common. When dysmaturity goes unrecognised, unrealistic expectations can be made of individuals based on their chronological age or some external benchmark.

The amount of research on FAS since the 1970s is claimed as ‘remarkable’, yet the absence of consensus on a range of diagnostic issues and of the variations in the face and brain arising from fetal exposure to alcohol is significant (Goodlett 2010, p. 579). This causes difficulties for those who cannot meet the diagnostic criteria, particularly if they were exposed to alcohol *in utero* but are

without the characteristic facial features. Goodlett argues the need for early identification of at-risk exposure, and also of phenotypic markers that can predict the varying neurodevelopmental trajectories of FASD: a theme which will remain a challenge into the future (2010, p. 581). The outcome of these studies today is a resolution, albeit a cautionary and controversial one, that the only safe preventive measure is abstinence.⁵

The number of individuals affected by FASD is frequently documented on websites and resource materials as greater than ‘Down syndrome, cerebral palsy and spina bifida combined’ (Mitchell 2005), and is variously predicted at 1 per 1000 live births (FAS and pFAS only) to 1.9 per 100 live births (the complete spectrum of FASD). Some consider these figures an underestimation, and predictions for all exposed individuals have been put at eight to ten times higher in some vulnerable population groups (Burd 2006; Kyskan et al. 2005). Recently, in the United States, Philip May and colleagues published a study of over 70% of all first graders enrolled in public and private schools who were assessed for physical growth, development, facial features, intellect and behaviour. The results revealed an estimated prevalence of between six and nine per 1000 children for FAS and between 11 to 17 per 1000 for pFAS, with the total prevalence rate for FASD estimated at 3.6 per cent of the population (May et al. 2014, p. 855). If this is accepted as a benchmark for predicting the numbers of Australians living with FASD, the condition may well affect the lives of more than 800,000 Australians (Australian Bureau of Statistics 2016).

4.2. FASD AND THE IMPACT ACROSS THE LIFESPAN

The life course of a person afflicted with FAS can be positively influenced by protective factors such as a stable and nurturing home life, an early diagnosis (linked with FAS only), and the absence of victimisation (Streissguth & Kanter 2002, p. 35). In the absence of protective factors, children living with FASD may, by adolescence, be at increased risk of early school leaving, with poor academic outcomes a result of their learning difficulties. Early school leaving impacts on employability, and without secure income there is increased risk of homelessness, of developing mental health issues, and of dependency on alcohol and other drugs (Streissguth, Bookstein & Barr 1996).

Those exposed to alcohol in the pre-birth environment and who have a post-birth diagnosis of FAS are more likely to engage early with disability and social support services; those with ARND are disadvantaged. Their otherwise normal appearance does not lead to expectations of FAS, so ‘deviant’ behaviours may give rise to a raft of diagnoses, assessments and interpretations; behavioural

⁵ Information gained from personal work and knowledge from work in the field.

modification strategies will be imposed, possibly from an early age. This is borne out by the fact that many affected individuals present as 'normal', bright, friendly and articulate, which paradoxically 'masks' the alcohol exposure (Streissguth et al. 2002, p. 35).

A child's history of multiple agency contacts, and a plethora of diagnoses and interventions like behavioural and medication-based therapies that either do not work or may exacerbate problems, are often key indicators of fetal alcohol exposure (Malbin 2011). Individuals living with the adverse outcomes of fetal alcohol exposure are often labelled according to their 'perceived' behaviours, without any understanding of their cause or any appreciation that their problem is a physical, brain-based condition. A child may be labelled as defiant, wilful, lazy or deliberate, and clinical and therapeutic interventions – even punitive responses – are aimed at promoting individual responsibility for behaviour change. The individual's self-perceptions of failure emerge as 'defensive' behaviours as the gap between environmental expectations and the abilities of the individual child widen (Malbin 2011). The lack of 'fit' becomes a primary contributing factor in an increasing tendency to truancy, alcohol and other drug use, victimisation, prosecution and conviction in the criminal justice system in later childhood, and perpetuation of 'defensive' behaviours in adolescence and adulthood. The likelihood of separation from family as a result of misunderstood 'unmanageable' behaviours and the child's non-responsiveness to intervention is increased.

Among girls with FASD there is a heightened risk of early and unplanned pregnancies, leading to a situation where FASD-affected individuals who attempt to parent, or who do not know how to parent, their own affected offspring are subjected to further systemic and community victimisation and blame for their failure.

In respect to crime, affected individuals are found by Streissguth and Kanter (2002) to be at greater risk of both victimisation and offending, with offending behaviour resulting in early and ongoing contact with the criminal justice system. The predicted consequences for individuals living with FASD can be profound, with early and ongoing encounters with the criminal justice system leads to the 'revolving door' pattern where the consequences of punitive juvenile justice responses, intended to manage undesirable behaviours, instead exacerbates them. Poor consequential thinking, hyperactivity, memory deficits and poor social skills may lead to breaches of court orders because the applied sentencing regime cannot be remembered.

The lifespan implications of fetal alcohol exposure attracted wider research attention by 1997. The Research Branch of Correctional Services of Canada published a report on FAS and its implications for correctional service (Boland et al. 1997). Central themes highlighted in the report are the implications of FAS/FAE across the lifespan; and the predictors of the impact of inattention, hyperactivity, impulsiveness, low intelligence, poor school achievement, antisocial behaviour and poor

parental child-rearing on crime (1997, p. 3). The likelihood that individuals affected by fetal alcohol exposure will come into contact with the criminal justice system is considered, and recommendations include pre-sentence screening and the appointment of advocates to support the development and application of appropriate individual needs-based programs, complemented by in-service training for all justice workers.

While not a subject area that can be adequately covered in this thesis, prisoner profiles do reveal a social history, life outcomes and behaviours (Cant et al. 2000) that somewhat mirror the secondary disabilities described in the FASD literature (Streissguth et al. 2002). Individuals living with FASD are probably more vulnerable to police interrogation practices, overtly admitting to criminal activities they may or may not have been involved in; early release is not uncommon because of their adoption of structure, routine and imitation of prison routine; but can inadvertently result in a ‘revolving door’ pattern of incarceration. Despite the friendly and often articulate responses of sufferers of FASD, studies reveal what appears to be a failure to understand standard type interrogation questions (Nanson 1997). Manifested secondary behaviours present a primary challenge to treatment and management and the multi-faceted physical, mental, financial and emotional stressors on families can be overwhelming (Gelo & O’Malley 2003, p. 1).

Traditional, yet widely applied cognitive/behavioural interventions derived from dominant professional discourses contribute to the lifespan impact of fetal alcohol exposure. My professional experience has seen the too common story of acquiescent individuals who live each day with unique presentations of physical, neurocognitive and/or developmental impairment which, in the absence of community understanding, perpetuate their ‘invisibility’. This is a story of the critical importance of understanding brain ‘difference’ (Malbin 2011), of the importance of empowering parents, carers and supporters as champion advocates, of the need for prevention across all levels – primary, secondary and early intervention for those affected by FASD and of the need to address inequities.

Reducing the economic burden through prevention has been demonstrated by economic cost estimates which since 1984 have been reported and contrasted with rising prevalence rates in the United States (Lupton et al. 2004). In 1980, the cost per individual living with FAS was predicted at \$163,000 per lifetime of care (Harwood & Napolitano 1985); by 1992 estimates escalated to a predicted total annual cost of \$2.9 billion (Harwood et al. 1998). By 1993, the National Institute on Drug Abuse estimated \$1.94 million as the annual health cost of the medical consequences of infant alcohol exposure (National Institute on Drug Abuse, 1992).

Several turning points have emerged from a plethora of research on FASD in the past 40 years to inform the evidence base: (i) that a much lower threshold of maternal alcohol exposure may cause fetal harm (Greenbaum et al. 2002); (ii) that prevention, including early intervention as a protective

factor, is important to offset the risk of secondary disabilities (Streissguth & Kanter 2002); (iii) that alcohol affects the developing structures of the brain (Malbin 2011), and (iv) that the numbers of individuals estimated to be living with the condition are potentially much higher than previously estimated (May et al. 2014). Ramsay (2010) reflected on the degree of global underestimation of the magnitude of the problem and of the intersection of multiple factors which combine to increase the severity of FASD: the amount of alcohol consumed and the pattern of exposure, the genetic profiles of mother and child, and environmental influences like malnutrition. There is a growing body of knowledge on the impact of ‘epigenetic remodeling during gametogenesis and after conception as a key mechanism for the teratogenic effects of FASD that persist into adulthood’ (Ramsay 2010, p. 27), and this is a current focus of research. It is anticipated that this research may answer the question of why one individual is affected differently from another when exposed to similar patterns of fetal alcohol exposure.

4.3. SUMMARY

No one can estimate the prevalence of FASD in Australia, but there is agreement among clinical and other experts that the problem is underascertained. One major impediment is that a variety of diagnostic instruments are used, leading to some clinical ignorance as to the application of FASD diagnostic criteria across a spectrum of conditions. The failure to determine the extent of the problem adds to a lack of acceptance of its seriousness. Hesitancy to diagnose FASD exists because the label, by default, names and attributes blame. Clinical discretion in applying alternative diagnoses for some individuals is a challenge. Combined with the current unrecognised status FASD has as a registered disability, these factors mean little evidence is available to convince public policymakers of the true scope of the problem. Individuals and families who live with undiagnosed FASD are therefore denied access to the levels of publicly funded support services required to manage daily life, making FASD an ‘invisible’ disability.

FASD policy interest in Australia since the turn of the century can at best be described as spasmodic, fluctuating between heightened interest evident in literature reviews or monographs, the convening of national forums and recommendations for action by Commonwealth governments, followed by gaps of inaction. The problem of FASD only reached the Commonwealth formal policy agenda in 2013 with the launch of a Commonwealth FASD Action Plan. Somewhat ironically, the details of that plan indicate a prevailing policy ideology that prevention is best left in the hands of medical and research elites, which hold the technical authority to guide government policy. Thus, FASD policy is not subject to wider representation or consultation, and is suppressed from the public agenda.

CHAPTER 5 FASD IN THE UNITED STATES OF AMERICA

In the previous chapter, some of the major events precipitating the recognition of different aspects of FASD as a public policy problem are documented. This chapter draws from archival data of events from the 1990s, extending the time frame of the previous chapter to cover four decades, from 1973 to 2013. It begins with a greater involvement in the 1990s of parent groups which became key advocates to raise the awareness of the risk of fetal alcohol exposure and to establish support organisations. Parent advocates pushed for greater attention to the life experiences of individuals living with FAS, their families, and the provision of online resources and information. However, most influence on policy in the 1990s came from politicians who knew first-hand the devastation caused by FAS in their home states. Collaborations of stakeholder individuals and organisations inside and outside government evolved to take advantage of this important source of influence. In this chapter, attention is given to the importance of collaborations; to research, separated into sections on gender and ethnicity; and to diagnosis. It concludes with archival information on the cost and prevalence of FASD.

5.1. DEMAND FOR PROBLEM ATTENTION

In 1989 Michael Dorris wrote and published an autobiographical account of a Native American boy he adopted from Alaska as a young college professor. His book was *The Broken Cord* and it, together with a television interview, contributed to the emergence of FAS as a recognised social issue, one which needed to be embedded in ‘the public consciousness’ (Streissguth, 2010). Dorris documented and publicly described his struggle to understand his son’s behaviours which mirrored typical behavioural patterns attributed to FAS, the difficulties he had in accessing information, and his struggle to access appropriate services (Streissguth 2010).

Often prompted and sustained by parents and caregivers, early grassroots organisations formed across the United States, including the Fetal Alcohol Syndrome Task Force formed by parents and caregivers in Idaho which spawned the Family Resource Institute on FAS, which still publishes the *FASTimes Newsletter* (FAS*FRI 2012). The Fetal Alcohol Drug Unit is credited with publishing the first FASD quarterly newsletter to be circulated globally. From 1991, *Iceberg* was produced by a parent/professional partnership, and made accessible online at a time when the internet was gaining momentum as a tool for public education. The newsletter documented developments in FAS study, particularly in scientific research, for twenty years, concluding in 2010. Clarren (2010) points out that this collaboration between professionals and families was important, for without families, ‘professionals might just look self-serving; without professionals, families may lack credibility in their specific requests’.

In the first instalment of *Iceberg*, a birth parent wrote of the approach to FAS at that time, highlighting the lack of clinical awareness and the consequences this had for individuals and families:

My fifteen-year-old daughter, has Fetal Alcohol Syndrome because I drank alcohol heavily when I was pregnant with her. It doesn't seem to make much difference that I didn't know the alcohol I was drinking could harm her, that my doctor suggested an occasional cocktail might be good for me: that I had the 'disease' of alcoholism and wasn't 'responsible' for my behavior. My feelings of guilt, shame and grief have still been overwhelming. (Vadheim 1991)

The Fetal Alcohol Syndrome Consultation Education and Training Services Inc.⁶ (FASCETS) is a different type of organisation, but an example of a recognised need to train parents and service providers in responding to FAS. Based in Oregon, FASCETS was founded in 1997 by Diane Malbin, a social worker who had already been providing education and training on FAS for a decade (Seo Oba 2012). The work of FASCETS challenged prevailing thinking about working with individuals and families, following the realisation by Malbin that perhaps behaviour is symptomatic of an underlying brain based condition and not deliberate. Malbin questioned the efficacy of behavioural/learning approaches to FASD interventions if the aetiology of presenting behaviours was symptomatic of brain dysfunction, and considered the diverse implications a different approach might have on parenting, education, mental health, justice – all systems (Malbin 2013, personal notes). FASCETS education and training introduced participants to what is now known as the 'Fetal Alcohol/ Neurobehavioral' (FA/NB) approach, an alternative paradigm for understanding the behaviours of those living with FASD. FA/NB has the aim of increasing understanding of FASD as a brain-based physical disability, and of preventing secondary defensive behaviours and improving outcomes. The approach requires rethinking and reframing interpretations of behaviours and the implementation of appropriate environmental strategies or accommodations (FASCETS 2013).

The FAS Community Resource Center in Arizona⁷ (Fasstar Enterprises) was established in 1995 with funding from a three-year FAS Prevention Project of the Governor's Council on Developmental Disabilities. The focus of primary prevention activities is raising awareness; secondary prevention targets women who have borne a child with FASD; it aims to reduce the secondary impacts associated with FASD. The Director, Teresa Kellerman, 'is an adoptive parent with 20 years' experience in successful FASD intervention' and the director of the FAS Community Resource Center. She began a parent support group which has met regularly since the Centre's establishment (FAS Community

⁶ More information on FASCETS is accessible online at <http://www.fascets.org/info.html>

⁷ More information on Fasstar is accessible online at <http://www.fasstar.com/>

Resource Center 2010). Kellerman noted in 2005 that ‘FASD is probably the number one health issue, the number one social problem [but] nobody realizes it. There is so much denial and misunderstanding that progress in the area of prevention is extremely slow’ (FASstar Enterprises 2005).

5.2. NATIONAL POLICY

A high-level example of collaboration is the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICC-FAS), created in October 1996 in response to recommendations from an expert committee from the Institute of Medicine (IOM). The ICC-FAS Committee noted that the responsibility for addressing the many relevant issues for consideration transcended the mission and resources of any single agency or program, and recommended that the National Institute on Alcohol Abuse and Alcoholism (NIAAA) chair an effort to coordinate federal activities on FAS and other disorders associated with prenatal alcohol exposure. This recommendation actualised the importance of collaboration. The ICC-FAS has a membership of representatives from the following agencies: the Department of Health and Human Services (DHHS); Agency for Healthcare Research and Quality (AHRQ); Centers for Disease Control and Prevention (CDC); Health Resources and Services Administration (HRSA); Maternal and Child Health Bureau (MCHB); Indian Health Service (IHS); National Institutes of Health (NIH); National Institute on Alcohol Abuse and Alcoholism (NIAAA); National Institute of Child Health and Human Development (NICHD); Substance Abuse and Mental Health Services Administration (SAMHSA); Department of Education, Office of Special Education and Rehabilitative Services; and Department of Justice, Office of Juvenile Justice and Delinquency Prevention (National Institute of Health 1996).

Ex-Congressman Tom Daschle provided inside government influence on FAS policy. He had represented the state of South Dakota, where prevalence among the Indigenous Sioux people at the time was estimated to be 25 per cent. He became instrumental in establishing the National Organisation for Fetal Alcohol Syndrome (NOFAS). NOFAS advocates at a federal level, representing almost forty state affiliates, one of which is the Minnesota Organisation for Fetal Alcohol Syndrome (MOFAS), established in 1998 by former first lady of Minnesota, Susan Carlson. MOFAS has nine regional family resource centres with the goal of offering families living with FASD support and help, and to give a voice to the FASD community on public policy matters (NOFAS 2013).

NOFAS believes that it is imperative for FASD to have as many allies as possible among elected officials and policymakers at every level of government (NOFAS 2013). Positioned outside government but with national influence, NOFAS affects policy development by being represented by federal agencies in formal collaborations, as in the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICC-FASD) and the National Taskforce on FASD which was first convened in 1999 by the Center of Disease Control. Both the National FASD Taskforce and the ICC-

FASD collaborations report directly to government: the ICC-FASD on strategies and achievements; the Taskforce on work to be done, and to promote and gain funding for preventive work. The National Taskforce is made up of various federal agencies and ten state-based groups, most of which are coordinating committees representing partnerships of concerned agencies. Current priorities support long-established research that ‘confirms that mental health and treatable behavioral disorders are common among individuals with FAS’ (NOFAS, 2013) and support for the proposed inclusion by the DSM-5 Task Force of ‘Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure’ in the very recent Diagnostic Statistics Manual-VI (American Psychiatric Association, 2013). At the time it was hoped that the inclusion of neurobehavioural disorder ‘could lead to standardized diagnosis, treatment, and reimbursement for practitioners serving the needs of persons with FASD, while maintaining the primary diagnosis as a medical condition’ (NOFAS 2013).

At a state level, the Fetal Alcohol Syndrome Interagency Workgroup (FASIAWG) was established in Washington State in 2005. On its website FASIAWG is described as representing a diverse spectrum of programs designed for individuals with FASD and their families. This network of educational, research, and clinical services responds to the legislative mandate to ensure the coordination of identification, prevention, and intervention programs for children who have FASD and for women at high risk of having children with FASD (FASIAWG 2013). In the time since its inception, some 25 multidisciplinary collaborations have been implemented, delivering a broad array of prevention programs including diagnostic evaluations, screening of foster children, increasing eligibility in disability and mental health, birth defects surveillance, advocacy and training, conferences and community support programs, educational materials, the formation of the FASD Alliance for collaborative research, public and legislative awareness programs, and research aimed at distinguishing FASD and co-occurring conditions.

The Center for Disease Control forged a four-year agreement with NOFAS to develop the ‘NOFAS Clearinghouse and Media Outreach Center: A Model of Collaboration, Communication, and Capacity Building’ project in 2010. The aims of this project were to ‘increase the availability and coordination of fetal alcohol spectrum disorders (FASD)-related prevention, intervention, and support services at the national, state, and local levels [and] increase awareness regarding FASD through the distribution and dissemination of accurate information through professional and public health networks and the media’ (NOFAS 2013). The clearinghouse connected communities and professionals to community resources and disseminated resources and materials. One strategy was to develop the NOFAS Affiliate Network and provide technical assistance and offer microgrants; another was aimed at tracking media interest and coverage on issues related to FASD, responding to media portrayals of related issues using ‘consistent messages’ and proactive engagement of the media to deliver ‘accurate coverage of the topics of alcohol use, pregnancy and FASDs’ (NOFAS 2013).

The groundwork has been laid to confront the serious public health problem presented by FASDs. It is reasonable, efficient, and humane to establish an integrated system of services for individuals and families affected by these conditions. This is a problem that can be dealt with, but momentum must be sustained. What is needed is well-informed public policy on FASDs and a clear, ongoing societal commitment to advancing research and ensuring essential services for persons with FASDs and their caregivers (Carmichael Olsen et al. 2009, p. 2).

5.3. FOCUS ON WOMEN AND ABORIGINAL COMMUNITIES

The published findings that linked maternal alcoholism with adverse fetal development coincided with *Roe V Wade*,⁸ a United States Supreme Court decision which was the culmination of decades of struggle by women activists asserting the right for women to have control over their own bodies, and hence the right to choose to terminate a pregnancy. The connection between maternal drinking and FAS was entrenched in medical and scientific thinking, and this legislation and the political cleavages that it heightened did not go unnoticed, particularly by feminist writers at the time. Armstrong, for example, proposes that the emergence of FAS occurred concurrently with other social trends and events, not least the sexual revolution of the 1960s and the politicisation of pregnancy and reproduction in the 1970s (2003, p.190). Armstrong questioned the uncertainty surrounding FASD and how, in the absence of precise information, medical knowledge is codified (p. 5). She linked the social determinants of risk with the use of medicine to manage it, which in turn was argued to reaffirm the social order (p. 9).

By the early 1990s, the Center for Substance Abuse Prevention had estimated that 4000 to 12,000 babies were born annually with signs and disabilities associated with FAS, and even more experienced the lesser disabilities of FAE (Substance Abuse and Mental Health Services Association 1993). The onus of responsibility for FAS was clear, with several funded programs designed to reduce women's alcohol and drug use in pregnancy. Legislation requiring the labelling of all alcohol bottles had been implemented in 1989; and in the period immediately following the legislation, Hankin (1994, p. 62–66) found an initial increase in FAS awareness and a decrease in alcohol consumption during pregnancy. Decreased alcohol use, however, occurred only in women whose drinking patterns placed them at low risk; women who drink heavily during pregnancy did not appear to be influenced by

⁸ On January 22, 1973, the United States Supreme Court handed down its landmark decision that the 'constitutional right to privacy extends to a woman's right to make her own personal medical decisions – including the decision to have an abortion without interference from politicians. Over 40 years later, Americans are still standing by this decision: In fact, 67% of Americans believe *Roe v. Wade* should remain the law of the land' (Planned Parenthood 2016).

warning labels. The primary prevention initiative was criticised: the labels lacked uniformity and were harder to see than US cigarette package warnings (Blume 1996); nevertheless, by 1997 seventeen states had enacted legislation requiring alcohol and pregnancy warning signs to be posted in liquor outlets and the distribution of a resource called ‘Screening for Substance Abuse During Pregnancy: Improving Care, Improving Health’ was published (Morse et al. 1997).

Under the banner of the Healthy Start Division of Health Resources and Services Administration (HRSA) maternal and child health division, the Healthy Start initiative began in 1991 ‘to reduce disparities in access and utilisation of health services, improve the quality of the local health care system, empower women and their families, and increase consumer and community voices and participation in health care decisions’. Healthy Start currently has 104 projects in 38 states, and all are implemented with a focus on alcohol screening with pregnant women and follow-up for the first two years postpartum, to redress ‘significant disparities in the health of mothers and babies’ (Health Resources and Services Administration). A crucial issue for the Healthy Start program was to improve substance abuse treatment, make early identification of alcohol use in women, and early detection of prenatal alcohol exposure. Findings from the 2006 evaluation of the Healthy Start projects found a significant level of attention was paid to ‘racial and ethnic disparities in maternal and infant health outcomes’, and 99 per cent of projects offered education to clients ‘inclusive of alcohol abuse’. Outreach programs, case management, health education and perinatal depression screenings were the four components of service delivery, with interconceptual care counselling encouraging a two-year spacing between pregnancies offered by almost all projects. Involving consumers through active participation was reported to be a feature of 92 per cent of Healthy Start projects (Health Resources and Services Administration).

The Fetal Alcohol Drug Unit at the University of Washington, Seattle, received a funding grant in 1991 from the Center for Substance Abuse Prevention to develop a demonstration project to help communities to deliver long-term advocacy and support mothers who abused alcohol and drugs during pregnancy. The Parent–Child Assistance Program has successfully served over 750 families in Washington State since its inception, and the model has been replicated at 14 other sites in States (Astley 2005, p. 29). In Northern California another prevention program took shape with the establishment in 1990 of the Early Start program (Leiberman et al. 2005, p. 62–64). Now a nationally recognised program for early intervention and treatment of substance-using women, the Early Start program ‘mirrors earlier, more traditional and holistic ways of caring for women’s health’ (p. 62). A key component of the program is the availability of a licensed substance abuse specialist whom women can visit during prenatal care visits.

The National Institute of Drug Abuse (NIDA) funded 21 perinatal projects to be implemented nationally in the early- to mid-90s. This was a joint effort by NIDA and multiple agencies, designed to

be inclusive of existing community services with a focus on treatment services for pregnant, substance-dependent women and their families. One example, the MOMS Project, was a major advocate for more treatment placements for women in the state of Washington, the development of therapeutic childcare onsite at chemical dependency centres, and creating more woman-oriented services in the state. There was an effort to monitor FAS among the women at the treatment centre and to educate the staff and patients about FAS. The MOMS Project facility eventually became the non-profit Perinatal Treatment Service (Astley 2005, p. 12).

From 1992 to 1997, the Center for Disease Control funded the FAS Diagnostic Prevention Network at the University of Washington to enable it to open the first interdisciplinary FASD Diagnostic Clinic in the state and conduct an FAS primary prevention project. The clinic was assessed as a point for identifying women at high risk for alcohol misuse who had had a child diagnosed with FAS, and targeting them for primary intervention. Over time the clinic generated a comprehensive, lifetime profile of 80 birth parents, a first step in the development of intervention programs to meet their needs. The project considered all life factors which enhanced or hindered the adoption of abstinence or practice family planning (Astley et al. 2000b).

Several recommendations were made: the implementation of state-wide networks to co-ordinate diagnostic clinics and facilitate early intervention; the provision of education and support centres for parents and public, with in-service training for service providers; the development of collaborative state inter-agency networks to enhance detection, diagnosis and service provision; the provision of funding for the development of clinical diagnostic tools to assess neurobehavioral effects; the modification of eligibility criteria for developmental disabilities to enable access to case management and support; the funding of residential or job training for adolescents and adults living with FAS/FAE; the full disclosure of medical case histories for children coming into care placements, and supports for those caring for children affected by FAS; and the prevention of the births of more children to high-risk parents through treatment, advocacy and birth control options offered to women experiencing alcohol problems (Streissguth et al. 1997, pp. 37–38).

This last recommendation added to the focused attention on women's use of alcohol, including building research on birth mothers to discover themes in their lives that might inform early intervention strategies, particularly with high-risk drinking women. One study of note contrasted the drinking patterns of pregnant and non-pregnant women between 1991 and 1995, with the objective of identifying the characteristics of pregnant women whose drinking was 'risky' (i.e., five or more drinks per occasion or at least seven drinks per week). Researchers used Behavioral Risk Factor Surveillance System data from 46 states and found 'pregnant women were one-fifth as likely as non-pregnant women to drink in at-risk patterns over the course of the study' (Ebrahim et al. 1999, pp. 1–7). The study reported the reduction in 'binge drinking was smallest for black women, and largest for women

under 30 years of age, and for those who had quit smoking'. The data on pregnant women from 1991 to 1995 found that 'risk drinking increased four-fold from 0.7% to 2.9% and frequent drinking among non-pregnant women remained stable (approximately 11%)' (Ebrahim et al. 1999, pp. 1–7).

In 1996 the National Institute of Health (1996) published findings from a National Pregnancy and Health Survey, the first nationally representative survey of drug use among pregnant women, finding that 18.8 per cent or 757,000 women reported drinking alcohol. Another study specifically examined the personal histories of mothers of children diagnosed with FAS and found that they began drinking early in their lives, had histories of severe unresolved childhood abuse, had mental health problems were involved in drinking subcultures, and feared abandonment by family or friends if they stopped drinking. Almost a fifth had 'alcohol-related organic brain dysfunction' (Clarren 1999, p. 9).

Kvigne et al. (1998) compared the life circumstances of Northern Plains Indian women with substance use problems with women from the same tribal group who abstained during pregnancy. Those in the former cohort were

more likely to be single, less educated, have less access to transportation, smoke, use other substances, and have alcohol dependence in their families of origin. They were also more likely to have experienced physical and sexual abuse. (1998, pp. 214–222)

Kvigne and colleagues reported that 56 per cent of the first cohort reported drinking in pregnancy, and almost half those with positive screening for alcohol use reported binge drinking.

Some of the first studies on FAS anywhere involved American Indians (Trujillo Lewis et al. 2011, p.2) and the focus of literature since then indicates that attention on American Indian women has continued so that more information is known 'about FAS in Native populations compared with the population as a whole. Trujillo Lewis and colleagues sought to learn more about any association between psychological distress and the birth of children with FASD, arguing that 'specific personal, behavioral, and social influences on maternal drinking is valuable [because once identified] the directions for prevention and intervention are clear' (p.16).

The emphasis on one population group has likely contributed to the perception that FAS is exclusively an American Indian issue, which may result in under identification of FAS in other ethnic groups' (Elliott & Hansen 2006, p. 341). Abel and Hannigan (1995) contributed what they termed 'provocative and permissive' issues in FASD-related research and proposed that certain ethnic groups were overrepresented in studies of people with FAS and FAE and low socio-economic status rather than race is the critical factor. Poverty, they argued, enables other risk factors such as drug abuse, multiparity and poor nutrition to compound the effect of alcohol on a fetus.

While prevention policy retained this focus, secondary prevention began to evolve as attention shifted to improved diagnosis and workforce training. In October 2001, the Substance Abuse and Mental Health Services Administration (SAMHSA) launched the FASD Center for Excellence, authorised by Congress in Section 519D of the Children's Health Act of 2000. The FASD Center for Excellence was mandated to explore innovative service delivery strategies; develop comprehensive systems of care for FASD prevention and treatment; establish a training service system for staff, families, and individuals with an FASD; and prevent alcohol use among women of childbearing age. To determine the basis of the FASD Center of Excellence, focus groups were held at 17 town halls and listening circles with first-nation communities. Town hall meetings were predominantly held with parents (adoptive) or service providers who were 'mostly white' and who expressed frustration with progress (SAMHSA 2004).

One documented example came from on-site visits to ten Indian communities in 2003 to examine clinical interventions and systems of care, to provide technical assistance and training, and to develop innovative techniques for preventing alcohol exposed pregnancies. The subsequent report highlighted the plight of Indian communities whose prevention or community awareness programs were 'person specific, not program specific' (SAMHSA 2004). Those representing tribal behavioural health or medical service providers advised on their experience. FASD prevention programs initiated by one individual in a health, social service, or education agency who was concerned about FASD had closed when the initiator moved on, and the interest went with the person (SAMHSA 2004).

A 2003 Center for Disease Control report on improvements to pre-conceptual health and health care noted that 'in addition to having chronic diseases, a substantial proportion of women who become pregnant engage in high-risk behaviors and contribute to adverse pregnancy outcomes'. Ten per cent of pregnant women and 55 per cent of women at risk for getting pregnant were reported to be consuming alcohol (Morbidity and Mortality Weekly Report 2006). The recommendations of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effects, and the data reported on in the Center for Disease Control report, supported the United States Surgeon General's decision to pregnant woman should not drink alcohol during pregnancy; that a woman who is considering becoming pregnant should abstain from alcohol; and that health professionals should routinely ascertain whether pregnant women and women who are considering becoming pregnant are consuming alcohol, and advise them not to (National Institute of Alcoholism and Alcohol Abuse 2008).

In response, Project Choices was launched, aimed at preventing alcohol-exposed pregnancies in particular high-risk settings, using motivational interviewing. The objective of developing a profile of the characteristics of those groups of women was to design a targeted focus to reducing the use of alcohol consumption among those women at risk of pregnancy. A second aim was to increase the use

of contraception by women ‘who do not reduce their alcohol consumption’ (Center of Disease Control 2014). Participating women were selected randomly to receive information and an intervention, or information only. The brief motivational intervention included four counselling sessions and a contraception consultation (Floyd et al. 2007, pp. 1–10).

Claiming that health care providers would more effectively prevent FASD if they knew which women to target, researchers made comparisons between Northern Plains Indian mothers of children with and without a diagnosis, and found those in the former group ‘were older, had fewer prenatal visits, more pregnancies, more mental health problems, and more injuries’, both total and alcohol-related. They concluded that women who presented with injuries or mental health issues should be ‘screened for substance use’, and acknowledged the ‘numerous needs’ that must be addressed to prevent future exposed pregnancies (Kvigne et al. 2003, p. 296).

Mengel et al. (2006, p. 494) advised that fetal alcohol exposure affects approximately one to three per cent of live births in the United States, and proposed reducing alcohol consumption or increasing ‘effective contraception among childbearing-aged women who engage in “at-risk” drinking’. They reviewed multiple studies to identify potential risk factors for maternal alcohol use, a list which included the age of the pregnant women if older than 30, unmarried, and Caucasian. High-risk women were likely to be college educated but could also be a member of special education population groups; they could have low or high socio-economic status and could be a member of a ‘poor’ Native American cultural group. A history of abuse, specifically physical or sexual abuse at any time of life, or physical abuse in the past year, was proposed as another risk factor. High-risk women were more likely to have experienced an older child’s apprehension by authorities and placement in foster or adoptive care, and to have borne a child diagnosed with FAS. Patterns of drinking were also identified as risk factors including early onset of alcohol use, a history of alcohol misuse, poly drug use and/or a male partner or family member who is a heavy drinker (Mengel, et al. 2006, p. 494–505).

A Public Education Program Manual was produced by SAMSHA in 2006 (Centre for Substance Abuse Prevention, Substance Abuse and Mental Health Services Administration; 2006). Other resources had become accessible online by this time, including two fact sheets titled ‘How to Have a Healthy Baby: be an Alcohol-free Mother-to-be’ in 2004 and ‘Preventing FASD: Healthy Women, Healthy Babies’ in 2007. Primary and universal prevention are part of the roles of SAMHSA, CDC and NIAAA, and as the research arm of government, this small number of ‘elite’ well placed and influential organisations delivered national leadership on fetal alcohol and FASD prevention.

Meanwhile, clients trying to taking up the offer of ongoing support and services revealed social and financial barriers including unstable housing, a lack of medical insurance coverage, limited access to transportation, a lack of child care, substance use issues and domestic violence (Maternal and Child

Health Bureau 2006, p. 13), and the ‘most significant challenges represent[ed] large social issues that Healthy Start case managers and other service providers may have limited resources to resolve’ (p. 20).

The National Taskforce on Fetal Alcohol Syndrome and Fetal Alcohol Effects was established in 2004 and co-ordinated by the Center for Disease Control and Prevention through the National Center on Birth Defects and Developmental Disabilities Fetal Alcohol Syndrome Prevention Team. The Taskforce discussions and deliberations were documented in a report called ‘A Call to Action’ in 2009 (Carmichael Olsen et al. 2009, p. ii). Ten recommendations were proposed to guide federal, state and local agencies to advance improvements and expand efforts regarding early identification, diagnostic services and quality research on interventions. The accomplishments of the Taskforce included the development of a national agenda; participation on the Scientific Working Group on Diagnostic Guidelines for FAS and ARND; endorsement of a definition of the term ‘Fetal Alcohol Spectrum Disorders’; a recommended update of the 2001 Surgeon General’s advisory on alcohol and pregnancy; and a report on reducing alcohol-exposed pregnancies (Carmichael Olsen et al. 2009, p. 10). Importantly, the report also highlighted challenging issues, including reducing the 12 per cent of pregnant women continuing to use alcohol or the one in eight fetuses at risk of fetal alcohol exposure despite the public health warning from the Surgeon General in 2005; the positioning of fetal alcohol spectrum disorders as medical and developmental; the need for more research on a diagnostic standard which could ‘delineate the entire fetal alcohol spectrum because many individuals with FASDs are unrecognized or misdiagnosed’, contributing to the absence of suitable treatment or interventions which are ‘incomplete or inappropriate’ (Carmichael Olsen et al. 2009, p. 1). The report also acknowledges the importance of collaboration ‘between government agencies, professional organisations, researchers, and families to address FASDs’ (p. 2).

By 2008, data collected between 2006 and 2007 indicated that almost 16 per cent of young pregnant women between the ages of 15 and 17 had consumed alcohol in the previous month at an average rate of 24 drinks (Substance Abuse and Mental Health Services Administration 2008). According to data collected over 15 years (1991–2005), one in every eight women had consumed alcohol during pregnancy; and this was noted to have remained largely unchanged over time. The study also revealed ‘the highest percentages of pregnant women reporting any alcohol use were aged 35–44 years (17.7%), college graduates (14.4%), employed (13.7%), and unmarried (13.4%)’ (Denny et al. 2005, p. 529–532).

5.4. THE SEARCH FOR A COGENT FASD DIAGNOSIS

In 1996 a publication from the National Institute on Alcohol Abuse and Alcoholism (Warren & Foudin, 2011) noted several important shifts in conceptualising FASD between 1995 and 2000. The

first was the use of the term ‘fetal alcohol’ by Riley et al. (1995), which changed the language from blaming maternal alcohol use or alcoholism to a less stigmatising term. The second was a proposed revision by the Institute of Medicine of the FASD diagnostic criteria. Stratton and colleagues had proposed FAS as ‘a classic example of a family problem’ and claimed FAS to be about a mother ‘who abuses alcohol’ and then has ‘additional affected pregnancies’ and an inability to care for her children (Stratton et al. 1996, p. vi). Estimates of lower levels of alcohol use in pregnancy as causal to fetal harm were claimed to be ‘premature’ (p. 27).

Within the IOM guidelines, diagnostic categories were proposed as cited in Roberts and Nanson (2000, p. 50): Fetal Alcohol Syndrome (FAS); FAS without maternal exposure confirmed but with evidence of facial dysmorphology, growth impairment and central nervous system dysfunction; partial FAS (pFAS), whose diagnosis required a confirmed history of prenatal alcohol exposure, facial dysmorphology, and either growth retardation or central nervous system abnormalities; Alcohol-related Birth Defects (ARBD), denoting the presence of congenital anomalies; and Alcohol-related Neuro-developmental Disorder (ARND), requiring a confirmed history of prenatal alcohol exposure and evidence of central nervous system abnormalities.

The importance of the inclusion of a category which eliminates the need for evidence of maternal alcohol use during pregnancy cannot be underestimated. The increasing number of children in care, of overseas adoptions and fostered adults, at a time when this category was unavailable, meant that maternal alcohol use in the histories of many children was unavailable or inaccessible. The inclusion of the term Alcohol Related Neurodevelopmental Disorders was coined by O’Malley (2000) as a substitute for the term ‘Fetal Alcohol Effects’, which was often mistakenly considered a milder form of FAS (Stratton et al. 1996). This revision was criticised by Astley and Clarren (2000) and cited in Roberts and Nanson (2000, p. 50) on the grounds that it implied alcohol was the ‘sole cause of fetal anomalies’.

The Center for Disease Control requested research be undertaken to build prevention knowledge, to ameliorate secondary disabilities for people living with FAS (Streissguth & Kanter 1997, p. ii). The research foci were the occurrence and range of secondary disabilities, risk and protective factors, and the development of a Fetal Alcohol Behavior Scale (FABS). Ten major areas of concern were identified; the findings revealed that 90 per cent experienced mental health problems, alcohol and other drug use; approximately 50 per cent over the age of 12 had experienced confinement or incarceration for mental health reasons or for alcohol and other drug dependence; 60 per cent had a disrupted school history through suspension, expulsion or ‘dropping out’; 60 per cent over the age of 12 had experienced trouble with the law; and about 50 per cent over the age of 12 had been reported for inappropriate sexual behaviour. For those over the age of 21, 80 per cent were reliant on dependent living and affected by problems with employment. Protective factors emerged as impacting singularly

or in tandem to ameliorate the onset of the secondary disabilities (Streissguth et al. 1997, p. 35) and included diagnosis before the age of 6 years and a stable home environment.

The success of fetal alcohol syndrome prevention activities in Washington State highlighted the establishment of the Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network (FAS-DPN) clinics, the development of the Fetal Alcohol Syndrome Facial Photographic Analysis Software, the FASD 4-digit Diagnostic Code, the Foster Care FAS Screening Program and ‘the collection of Pregnancy Risk Assessment Management System data on maternal use of alcohol’ (Astley 2004, p. 344–351). By 2001 the Fetal Alcohol Syndrome Diagnostic Prevention Network (FAS DPN) based at the University of Washington had completed work on the FAS 4-Digit Diagnostic Code, described as ‘a comprehensive, objective, case-defined diagnostic method designed for use by an interdisciplinary diagnostic team’. The 4-Digit Code is used by the Washington State FAS Diagnostic and Prevention Network of clinics and offers a comprehensive and ‘user friendly’ manual of information on all aspects of FAS – diagnostics and assessment, prevention and intervention. Astley (2004) described a multi-disciplinary clinic in Washington DC as focusing on the need to provide families with information in four broad areas: medical, psychiatric/psychological, educational, and social. The clinic provided diagnosis for all ages, with the majority of patients aged between 5 and 15 years.

Astley et al. (1999) argue that the 4-digit diagnostic code based on measurements of growth, dysmorphology, central nervous system dysfunction, and alcohol exposure is capable of 256 outcomes with ‘corresponding clinical data [that] better characterize the full spectrum of disabilities’. There is acknowledgement that diagnosis is not ‘straightforward as the individual ages’, and diagnosing adults is ‘particularly challenging’ (Stratton et al. 1996; in Roberts & Nanson 2000, pp. 50–51). Accuracy of diagnosis is further complicated when children at risk of fetal alcohol exposure are traumatised by post-birth abuse and neglect and present with behaviours related to these post-birth experiences. A point is made about the difficulty of distinguishing behaviour as resulting from fetal alcohol exposure, from ‘the child’s living environment ... or some combination of the two’ (p. 53).

5.5. IMPROVING SYSTEMS’ CAPACITY TO RESPOND

Beginning in 2002, nine Regional Training Centers across regional United States were established through funding from the Center of Disease Control. In the funding round 2011–2014, five centres were established. In the Arctic region, the training center is based at the University of Anchorage, Alaska; in the Frontier region, in Nevada; in the Great Lakes region the centre is in Wisconsin; the Midwestern centre is in Missouri and the Southeastern centre in Mississippi. The work of each Regional Training Center is based on the FASD Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice (CDC 2002), a collaboration of the first FASD

Regional Training Center, the Center for Disease Control and the National Organisation on Fetal Alcohol Syndrome (NOFAS).

The purpose of each of the Regional Training Centers is the development, implementation and evaluation of 'educational curricula regarding FASD prevention, identification, and care', and the inclusion of this curriculum 'into the training programs at each grantee's university or college, into other schools throughout their regions, and into the credentialing requirements of professional boards' (Center of Disease Control, 2013). Continuing the focus on women of childbearing age, there are set competencies aimed at preventing alcohol-exposed pregnancies through screening and brief interventions, referrals, and case management using applied addiction therapies. Training programs also cover the screening, diagnosis and assessment of individuals of all ages for FAS, and focus on building participant skills cognisant of 'ethical, legal, and policy issues related to FASDs' (Center of Disease Control, 2013).

In 2008 researchers sought to determine what human services professionals already knew or wanted to know about FAS. The aim was to first measure knowledge, attitudes and beliefs, particularly of those who worked in child welfare/child protection, foster care and Medicaid; 'and secondly, to use the knowledge to inform and train resources' (Caley et al. 2008, pp. 119–120). A self-administered survey revealed a strong belief in an abstinence focus (p. 120) and 45 per cent agreement in similar rates of occurrence of FAS across 'all socio-economic groups of society'. Fewer than 47 per cent were able to recognise the physical features of FAS, and awareness of risk for fetal alcohol exposure among their client group was low (80%). The majority reported no training and 70 per cent felt unprepared to identify, manage or co-ordinate treatment (Caley et al. 2008, pp. 119–120).

5.6. PREVALENCE AND COST

In 1998, the United States was reported to have invested '\$9.3 billion on programs for the developmentally disabled [and] CASA estimated that at least nine percent or \$837 million of state costs for programs for the developmentally disabled are a result of Fetal Alcohol Syndrome'. When compared with the costs of tobacco and other drugs, the costs of alcohol are enormous (alcohol \$149.2 billion; tobacco \$79.4 billion; other drugs \$18.7 billion). Approximately four per cent of the alcohol budget is devoted to prevention and treatment (Center for Addictions and Substance Abuse 2005, p. 18).

In the early part of the decade 2001–2010, estimates were that at least '40% of all pregnancies would have some exposure to alcohol before birth' (Centers for Disease Control, 2004) and 14.8 per cent of females of childbearing age (18–44) indicated at least one binge drinking session in the previous 30 days (Morbidity and Mortality Weekly Report 2002). Within two decades, three to five per cent of

fetuses were estimated as heavily exposed to alcohol (Herrick et al. 2011, p. 44) and 7.6 per cent of pregnant women reported using alcohol, with 1.4 per cent of this group disclosing use in the previous month (Morbidity and Mortality Weekly Report 2006–2010).

In the same year that the *Seattle Post-Intelligencer* (2005) published an article on the prevention of FAS, claiming that the alcohol industry ‘buttresses’ its position by invoking a disease model of alcoholism and asserting that problem drinking occurs only among a small number of troubled individuals, a report called ‘Shovelling It Up II’ (Center for Addictions and Substance Abuse 2005) was published. In this report, the total government spending linked to alcohol was estimated at \$149.2 billion a year, which the authors claimed was ‘more than 60 times as much to clean up the devastation substance abuse and addiction impacts on children as they do on prevention and treatment’. Of this vast investment, ‘\$960.0 million in state costs for the developmentally disabled as a result of Fetal Alcohol Syndrome’ was estimated, with the largest share for children in education (Center for Addictions and Substance Abuse 2005, p. 17). School costs linked to substance abuse and addiction include increased special education for those with FASD (Center for Addictions and Substance Abuse 2005, p. 17).

In the 1980s and 1990s the prevalence of FAS in the United States was estimated at between ‘0.5 to 2 cases per 1000’, and FASD prevalence studies were ‘most frequently carried out where there are a large number of FAS cases to be found’ (May & Gossage 2001). Researchers cautioned that if findings were then applied to the general population, ‘the prevalence of FAS may be overestimated’ (May et al. 2009, p. 176). With this in mind, May and Gossage reviewed FASD prevalence studies which used one of three different approaches. The first was passive surveillance, an approach using existing records to identify cases ‘at risk’ for FASD (p. 178). The second approach was clinic-based studies involving screening in prenatal clinics. As women chose to participate or not and the highest-risk women were often not regular attendees, the higher-risk drinking population group was often underrepresented. Clinic-based studies conducted in public health systems on the other hand, often dealt with disadvantaged women, so their data often over-represented the prevalence of FASD (May & Gossage 2009, p. 179). The third method was active case ascertainment, which was determined to be the most reliable approach due to its application of on-site assessment and diagnosis; however, the approach was labour- and resource-intensive and the recruitment only of ‘at risk’ women and their children was deemed selective (May & Gossage 2009, pp. 181–182). The authors reported ‘that the prevalence of FAS in typical, mixed-racial, and mixed-socioeconomic populations of the US is at least 2 to 7 per 1,000’ (p. 189). In respect to the complete spectrum, the researchers estimated a current prevalence rate ‘in populations of younger school children ... as high as 2–5% in the US and some Western European countries’ (p. 190). The results indicated an increased prevalence in school populations, and therefore in the general population, than previously estimated.

The National Organisation on Fetal Alcohol Syndrome (NOFAS) predicted in early 2012 that an estimated 40,000 fetal alcohol-exposed babies will be born each year in the United States. According to the Substance Abuse and Mental Health Services Administration, this equates with ‘up to 1 in 20 births’. It ‘can cost nine times as much to take care of [children with fetal alcohol disorders] as a healthy child’: which translates to a cost of ‘as much as \$2 million’ for each child over a lifetime. This led to a prediction that the cost of health care for those living with diagnosed FAS would reach an estimated \$6 billion, with costs escalating ‘sharply’ if the complete spectrum and impact of fetal alcohol were ‘factored in’ (National Organisation on Fetal Alcohol Syndrome, 2012). The estimate matches the one proposed by the Fetal Alcohol Syndrome Interagency Workgroup Report to the Governor’s Council on Substance Abuse in 2007 (Fetal Alcohol Syndrome Interagency Workgroup, 2007), a conservative estimate of \$2 million per lifetime of care for each individual living with FASD. The Fetal Alcohol Syndrome Interagency Workgroup contrasted this with an estimated \$10,000 per individual required to prevent FASD.

5.7. SUMMARY

The story from the United States suggests that the search for prevention opportunities since the early 1970s has been often dominated by duplicated research funded by major national health institutions, mandated by Congress to report on how best to target higher-risk drinking women and to determine prevalence rates for specific population groups in order to target investment. From the outset the focus has been on high-risk drinking women, and this has generally translated as Native American communities and other population groups identified by lower socio-economic indices. Despite the evidence that social and environmental factors influence higher-risk alcohol use (including poverty, violence, advanced maternal age, number of pregnancies, previous births of a child with FAS, cohabitation with a male partner who drinks heavily, and particularly socio-cultural values), these seem to be ignored.

The NIAAA holds leadership in the national effort to reduce alcohol-related problems by conducting and supporting research in a wide range of areas including genetics, neuroscience, epidemiology, health risks and benefits of alcohol consumption, prevention, and treatment; coordinating and collaborating with other research institutes and Federal Programs on alcohol-related issues; collaborating with international, national, state, and local institutions, organisations, agencies, and programs engaged in alcohol-related work; and translating and disseminating research findings to health care providers, researchers, policymakers, and the public. The NIAAA continues to fund a large and specific FASD (\$30m) research program, with projects covering prevention, diagnosis and ‘ameliorative interventions’ and the treatment of women with alcohol use disorders, and supports collaborations like the Collaborative Initiative on Fetal Alcohol Spectrum Disorders. This

multidisciplinary consortium aims ‘to accelerate the translation of key research findings by fostering collaboration and coordinating clinical, basic, and translational research’. CIFASP also seeks to determine ‘the prevalence of FASD among school-aged children in several United States communities ... using active case ascertainment methodology’. NIAAA supports the annual meeting of the FASD Study Group and the Prenatal Alcohol and Sudden Infant Death Syndrome and Stillbirth (PASS) Network. The work of the latter group is investigative, examining ‘the role of prenatal alcohol exposure and SIDS, stillbirth and FASD’ (NIAAA 2012).

Despite all that has been attempted to prevent fetal alcohol exposure and FASD, mandates call for prevention in specific population groups based on evidence of social and environmental contributing factors, at a time when the social determinants of women’s health and wellbeing are rarely addressed in the literature. This is evident in an April 2015 presentation to the American Psychological Association by Kenneth Warren, Deputy Director of the NIAAA; Professor Ed Riley, Professor of Psychology and Director of the Center for Behavioral Teratology at San Diego State University; and Kathleen T. Mitchell, Vice President and national spokesperson for the National Organization on Fetal Alcohol Syndrome (NOFAS). For Riley, the challenge of accurate diagnosis is to account for the myriad symptoms and signs of fetal alcohol exposure: ‘some will have the classic facial characteristics associated with FASD, others may have no outward morphologic signs but still have the brain impairments associated with FASD’. Riley also speaks about the reality that only half of all paediatricians are confident in making a diagnosis of FASD, and how this impacts on access to treatment. Mitchell, speaking from personal experience, describes her lack of awareness of the dangers of alcohol when she was pregnant in the 1970s and stresses the need to understand that most women do not know they are pregnant when they drink, or are unaware of the dangers. She points out that most women do not drink to harm their unborn child, yet may face prosecution and stigma if they seek help. Warren points out that half of all pregnancies are unplanned, so many unborn children are exposed to alcohol prior to confirmation of a pregnancy: this indicates that a change to the social norms surrounding drinking behaviour need to be encouraged.

Consistent prevention messages and increased public awareness of the risk of alcohol use in pregnancy, the limitations of current diagnostic criteria, the need to train the other half of all paediatricians, and a broader population-based focus instead of the discretionary selection of some women and some communities are issues that resonate through this chapter on FASD in the United States. This research now turns to Canada to determine if the story there is similar or different.

CHAPTER 6 FASD IN CANADA

Active, formalised collaborative partnerships between provinces and territories in Canada encourage strong professional voices on behalf of women and stress the importance of including Aboriginal people in policy decision-making, although archival records show that attempts by government to deal with FASD still focus on identifying and targeting those women drinkers deemed at ‘higher risk’ and who live in Aboriginal communities. This is moderated by collaborations of key advocates who continue to push for a more accommodating approach, taking account of the lived experiences of women and the impact on Aboriginal communities of colonisation and alienation.

6.1. DEMAND FOR PROBLEM ATTENTION

The role of parents as key advocates in the 1990s is evident. In the early 1990s, information and resources on FASD for parents and families was limited in Canada, and parent knowledge grew at the same time that online information became much more accessible. Some key advocating parents and a small group of professionals were aided by politicians and public servants who, as adoptive parents of children living with FASD or who were interested in raising public awareness, articulated their demands inside government. Initial demands were for more research, programs and services for those living with FASD, and improved recognition and response from the health, social services, justice and employment systems (Legge et al. 2000).

Parents, ‘particularly foster and adoptive parents, have been and continue to be key catalysts for action’ (Legge et al. 2000, p. 9). Audrey Salahub, for example, sought help for her child at a time when information and resources on parenting a child with FASD were so limited that the ‘Public Health Unit had one video’ on FAS (Salahub, 2010). By 1992 the British Columbia FAS Resource Group was established, with the broad aims of hosting ‘national conferences; undertaking research; and advocacy for attention to prevention’ (Ministry for Children and Families, British Columbia, October 1998). The following year, a group of interested people from the community of Maple Ridge, British Columbia, including Salahub, initiated a coordinated and strategic process to address FASD. This grassroots-based group developed and implemented a community action plan which resulted in the creation of the Fetal Alcohol Spectrum Disorder Society of British Columbia. A conference on FAS was convened in 1995 and, as an indication of interest in the problem, 300 people attended, including representatives from 50 organisations. Ms Salahub was influential in the establishment of

the Asante Centre⁹ for diagnosis, assessment and education in 2000, and is the current executive director.

Another key parent advocate is Jan Lutke. Ms Lutke became involved in FASD advocacy over three decades ago, following the adoption of her daughter when the child was five. This child had a diagnosis of FAS and a complex background; at that time there was no help available. Lutke remarked that ‘if there was no one else, we had to do what we could ourselves’ (2011). She is the current clinical research manager for CanFASD Northwest and a past co-chair of the former National Advisory Committee on FASD to Health Canada. She is a formidable advocate for those living with FASD: she chaired the former FASD Provincial Consultation Group to the Province of British Columbia, co-wrote the on-line FASD curriculum of the Justice Institute of British Columbia, and instructs both the Justice Institute and the Ministry for Children and Families on core curricula on FASD. She is the founder and former director of the FAS Support Network of British Columbia, and the senior consultant to FASD Connections, an organisation dedicated to helping adolescents and adults with FASD and their families. She also sits on numerous FASD provincial and national advisory committees (Canada NW FASD Partnership, 2012).

In Hamilton, Ontario, in the Eastern provinces of Canada, a small grassroots group formed the Fetal Alcohol Support Network in early 1991 to assist parents of children living with FASD. The group noted the limited information available on FAS in Canada at the time. Leadership emerged with advocacy from Val Surbey, a concerned parent who is acknowledged as the driving force in the establishment of a listserv for FAS discussions through a grant from the Canadian Centre for Substance Abuse, an organisation which is jointly funded by the alcohol beverage industry and the Canadian government. Demand for Fetal Alcohol Support Network support services evolved however, by 1999, the Canadian Centre for Substance Abuse had relinquished patronage. Current convener Bruce Ritchie (2005) claimed this shift resulted from online discussion about class-action lawsuits against the alcohol industry. Renamed FASLink, the online listserv continued as a voluntary organisation providing support and resources to over 400,000 parents, caregivers and interested persons each year; it holds archives of more than 100,000 FASD-related documents. The success of Faslink is attributed to its independence from government and the alcohol industry, and to the transparency of its contents – possible because it receives no funding from government and steadfastly

⁹ Information on the Asante Centre can be accessed online at <http://www.asantecentre.org/>

refuses 'to accept funding from the beverage alcohol industry' (Ritchie, personal communication 2005).

FASWorld was founded in Ontario in 1999 by parents Bonnie Buxton and Brian Philcox, with a United States parent, Teresa Kellerman, from the FAS Community Resource Center in Arizona. This group launched a worldwide grassroots movement based on a ninth hour, ninth day, ninth month concept and encouraged participation in an awareness-raising event organised across e-mail listservs that invited communities to participate. This is now known globally as International FAS Awareness Day. FASworld is described as 'a coalition of individuals and support groups across Canada who are dedicated to the elimination of FASD and supporting the parents and caregivers who strive to provide appropriate assistance to those who struggle with the various disabilities inherent in FASD'. Support groups operate independently across Canada, responding on local community need; there is some limited sharing of resources and parenting strategies. With their lack of coherent collaboration, they have no significant impact on persuading governments and social agencies to address the urgent needs of those most affected by FASD (FASWorld 2013).

6.2. NATIONAL POLICY

The Canadian Government Standing Committee on Health published 'Fetal Alcohol Syndrome: The Preventable Tragedy' as early as 1992 (Loney et al. 1994) using the Ottawa Charter for Health Promotion (1986) as a framework for prevention. There was early recognition that FAS was inseparable from 'the complex social, physical and economic environments' affecting alcohol consumption. A comprehensive, intersectoral approach inclusive of Aboriginal representation to address FAS was determined and the consultation process accommodated different perspectives, experiences, and knowledge (Bouchard 1992).

Strategies were advised as necessary to overcome the social norms regarding drinking during pregnancy (Health Canada 1992, p. 20) which was supported by the results of a Situational Analysis completed by the Canadian Centre for Substance Abuse in 1999. This comprehensive overview of FAS/FAE in Canada at the close of the 1990s collated 239 responses from a national survey, including a profile on the scope of activities at that time by type of intervention and target group. The profile of activities related to FAS were categorised as prevention, identification and intervention; community supports, research and policy as decision-making supported all categories ((Legge et al. 2000, p. 1).

Of the 239 participating organisations, 72 per cent were based in western Canada, with British Columbia identified as the most active jurisdiction. Primary prevention activities were prevalent, with a focus on women in pregnancy or in the pre-pregnancy phase of life (50–60%); and 51% of respondents reported active involvement in local coalitions or committees in the western provinces

(Legge et al. p. 7). Intervention services for children aged 0–6, adolescents and young adults were identified, but most respondents (77%) reported that FAS/FAE was only one of the issues their particular agency dealt with. Activities in education, justice and employment were reported to be few, suggesting most participants who reported on activities came from health settings.

By 1999 the Canadian government had established a national website, was working with provinces and territories to develop a national public campaign on the risks of alcohol use in pregnancy, and had completed a telephone survey that revealed few Canadians understood the serious impact of FAS/FAE (Health Canada Update 2000). The Canadian government hosted the first national forum on FAS/FAE (Legge et al. 2000) and released information and feedback on its FAS/FAE initiative led by the Population and Public Health Branch.

Promoting collaboration and building a national profile across Canada was the purpose of the National Action Plan on FAS/FAE (Health Canada 1999). The National Action Plan involved all governments: national, provincial, regional and community, across the sectors of education, health, social services, justice and corrections (Legge et al. 2000). The six key areas of focus considered various levels of prevention: raising public awareness, training, early identification and diagnosis, services integration and future funding for building the capacity to deliver services. These national initiatives coincided with a publication by Canada's Drug Strategy Division which reviewed best practices on FAS/FAE and the effects of substance use in pregnancy (Roberts & Nanson 2000).

The Public Health Agency of Canada released a Commonwealth document 'FASD: A Framework for Action' in 2003, claiming a provincial/ territorial and national estimated prevalence rate of '9 babies in every 1,000' affected by fetal alcohol exposure (Public Health Agency of Canada, 2005).¹⁰

Acknowledging that different methods produce different rates of prevalence because of the inconsistencies in, and sometimes the unreliable sources of, data from provincial and territorial studies, Tough (2009) concluded that no official Canadian statistics currently existed, and information provided by the Institute of Health Economics (2009, p. 7) revealed that the Public Health Agency of Canada estimate was based 'on the extrapolation of US data'. The Institute advised how the accuracy of Canadian data could be improved through 'simple, cost effective' surveillance and screening tools, beginning with determining of how many pregnancies are exposed to alcohol.

The Public Health Agency of Canada held a national thematic workshop on FASD in Ottawa in 2005 to identify and prioritise issues of national significance in FASD as they related to the development of

¹⁰ This estimated prevalence rate was repeated in an update of the Framework published in 2012 (PHAC 2012).

the alcohol portion of the National Framework for Action on Substance Use and Abuse; and to identify areas for linking this framework with the National Framework on FASD. The implied outcome was proposed as an opportunity to build and strengthen partnerships within the FASD community. Participants included individuals living in families with children with FAS, front-line workers, national non-government organisations, regulatory bodies, practitioners, researchers, academics, and federal and provincial government representatives, with newer partners including groups committed to supporting efforts to address FASD, such as the alcohol beverage industry. Together, the report of proceedings highlighted a demonstrated commitment to ensure FASD remains high on government and public policy agenda (Canadian Centre for Substance Abuse 2005).

The 2005 revised Commonwealth ‘FASD Framework for Action’ followed an earlier guide (Public Health Agency of Canada, 2003) but remained largely unchanged. It recognised four conditions across the FASD spectrum and importantly, the language recognised FASD as a ‘multi-faceted, public health and social issue that affects Canadians in all walks of life, in all regions of the country’ (Public Health Agency of Canada, 2005, p. 8). The policy document claimed, ‘FASD is not just a women’s issue or an Aboriginal issue – we are all invested in finding solutions’ (Public Health Agency of Canada, 2005, p. 24) – somewhat ironic, given the continued focus on alcohol use by women. The Framework is structured around five broad goals aimed at increasing public and professional awareness: the development and increased capacity of services to meet the needs of affected children, youth, adult, families and women who may use alcohol during pregnancy; national screening, diagnostic and data reporting tools; expanding knowledge and facilitating information exchange; and increasing commitment and support for action to address FASD (Public Health Agency of Canada, 2005).

6.3. PROVINCIAL/TERRITORIAL COLLABORATIONS

In the Western provinces and territories, a cross-jurisdiction partnership called the Prairie Province Fetal Alcohol Syndrome Partnership of Alberta, Saskatchewan and Manitoba formed in 1998, recognising that co-ordination and collaboration to prevent the problem and support those affected by FASD were priorities. A Partnership symposium in the same year focused on prevention strategies for drinking women at high risk of bearing a child with FAS, followed by a conference in Alberta aimed at sharing resources and skills, and to learn from experts in the field. A year later in 1999, the first practice symposium on diagnostic issues took place in Manitoba and the Yukon, and in the same year the Northwest Territories and Nunavut joined the Prairie Province Fetal Alcohol Syndrome Partnership, leading to its renaming as the Prairie Northern FAS Partnership (CanFASD Partnership 2014). Legge and colleagues noted several key developments including the expansion of the Prairie Province Partnership to the Prairie Northern FAS Partnership; a working group supported by Correctional Service of Canada; Health Canada’s National First Nations and Inuit Steering Committee

development of a National Framework for the First Nations and FAS/FAE Initiative; and the formation of Health Canada's National Advisory Committee on FAS/FAE (Legge et al. 2000, p. 10).

In 2001, British Columbia joined the Partnership of seven provinces and territories, and a name change followed: The Prairie Northern Pacific FAS Partnership. By the close of 2002, a symposium in Saskatchewan had covered the role of primary health in recognising and diagnosing FAS, identifying high-risk behaviours in pregnant women, the role of psychological testing and assessment, and the development of treatment plans. A Partnership conference in May 2001 focused on FAS, as this impacted on young people. The next year, prevention strategies for high-risk drinking women was on the agenda at a Conference event in the Northwest Territories, and a second conference in the Yukon focused on integrating services for persons with FAS across their lifespan.

A symposium in Nunavut in 2003 explored community responses in the raising and teaching of children (Canadian Northwest FASD Partnership 2010) while a second symposium in British Columbia the same year focused on identification and support for 'at-risk women and individuals potentially affected by prenatal alcohol exposure'. To incorporate more inclusive terminology to describe the spectrum of fetal alcohol-related disabilities and to be more internationally recognised, the Partnership's name was changed to the Canada Northwest FASD Partnership (Canada NW FASD Partnership 2013).

By 2005 the Canada North West FASD Partnership constituted an intergovernmental 'alliance of seven jurisdictions working towards the development and promotion of an interprovincial/territorial approach to prevention, intervention, care and support of individuals affected by Fetal Alcohol Spectrum Disorder' (Canada NW FASD Partnership 2009). The aims of the Network were to identify all FASD-related research projects, evaluate projects and consult with accepted network groups. CanFASD values research that has meaning for families, governments and stakeholders, and requires its partners to use appropriately sensitive language when communicating about FASD, in recognition of its complexity. There are four streams of research: diagnostics, prevalence, prevention and intervention. Within each stream are Network Action Teams involved in publishing work, presenting findings, working in collaborative committees, and identifying funding opportunities at local, regional, provincial, national and international levels (Canada NW FASD Partnership, 2013).

The Network Action Team on research, has over '40 active members' from across the country and works with 'a broad spectrum of organizations and institutions, ranging from the British Columbia Association of Pregnancy Outreach Programs to the Centre for Northern Families in Yellowknife, to Healthy Child Manitoba, to the Izaak Walton Killam (IWK) Health Centre in Halifax.' Team members have individual expertise in particular areas such as conducting research into women's substance use and other health-related women's issues; may be engaged in direct community-based service delivery;

providing expertise in ‘health education, psychology, sociology, nursing’ or epidemiology, First Nations and Inuit health, and public health, health policy and planning. Program evaluation and knowledge translation are topics covered in face-to-face and virtual meetings, and networking promotes an online community of practice (Canada NW FASD Partnership 2013).

The Government of British Columbia released a 10-year provincial plan for FASD in 2007 called *Fetal Alcohol Spectrum Disorder: Building on Strengths 2008–18* (Government of British Columbia 2007). This most recent strategic plan was built on the formal FASD Strategic Plan of 2003, the first of its kind in Canada (Christensen 2007, p. 1); it is the work of nine provincial government ministries and focuses on FASD prevention, early identification and support. Six strategic objectives aim to make British Columbians aware of the risk of alcohol and substance use in pregnancy; make support systems accessible; make access to focused intervention and support easier for parents; provide timely diagnosis and assessment; facilitate access to lifelong intervention and support; and build service systems which are ‘coherent, integrated and co-ordinated’ (Government of British Columbia 2007) and backed by strong research and evaluation.

Preceding the release of the Strategic Plan, the British Columbia Ministry of Education established a Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD) in 2006 (British Columbia Ministry of Education 2016). The aim of the online site and resources was ‘to increase educators’ capacity to meet the learning needs of students with Fetal Alcohol Spectrum Disorder’. Linda Reid is acknowledged for her contribution ‘inside government’ and was co-chair of the Canada Northwest Fetal Alcohol Partnership in 2004–05. She is a co-signatory to the British Columbia FASD Strategic Plan as Minister of State for Early Childhood Development.

A cross-sector partnership formed in Alberta in 1998 and in 2003 became the government-initiated Alberta Cross Ministry Committee on FASD responsible for the development of a ten-year strategy for the province (Alberta Government 2015, p. 3). In 2007–08, \$4 million from the Alberta Government was secured by Alberta Cross Ministry Committee on FASD to implement the strategy, with a further \$16.5 million allocated between 2008 and 2010. The Alberta Cross Ministry Committee on FASD reported some success, including the establishment of twelve functioning FASD service networks operating across the province that provided mentoring services (prevention); assessment, diagnosis and direct supports and services for individuals affected by FASD and their caregivers across the lifespan; and increased access to FASD assessment and diagnosis services for adults and children, provided by multidisciplinary teams (Alberta Government 2015, p. 3). By 2011, 28 diagnostic and assessment clinics were anticipated to be operational, as well as the planned expansion of the Parent–Child Assistance Program from 11 to 21 programs (Alberta Cross Ministry Committee on FASD, 2009/10). The most recent published review of the plan reveals many successes, although with slightly

fewer diagnostic clinics (total 24) and Parent–Child Assistance Programs (total 18) operating in the province than anticipated (Alberta Cross Ministry Committee on FASD, 2015, pp. 6, 8). Future recommendations include wrap-around and mentored support for those living with FASD; a shared understanding of the sustainability of the work across all service networks; clear, measurable outcomes in efficiency and effectiveness across all streams; improved data collection to enable consistency and demonstrate economic value for funding investment; the formation of sub-committees to have oversight of stakeholder engagement and collaboration; and appropriate levels of core funding to ensure the goals of the strategy are achieved (Alberta Cross Ministry Committee on FASD, 2015, pp. 21–22).

6.4. NATIONAL HEALTH ORGANISATIONS

A FASD National Conference, ‘Fetal Alcohol Spectrum Disorder; Equality of Access: Rights and the Right Thing to Do’, was held in Victoria, BC in February 2005. The conference description advised of the ‘growing awareness of the failure to accommodate the needs and rights of individuals with FASD within society’ and the resultant ‘diminished access to health, education, social services, and justice’ (Interprofessional Continuing Education 2005). In 2009 the Institute of Health Economics Consensus Conference on FASD was held in Edmonton, Alberta (Institute of Health Economics 2009). Questions were posed to jurors on FASD and its diagnosis; the prevalence and incidence of FASD in different populations; improved reporting; the consequences of FASD for individuals, their families and society; how FASD might be prevented; policy options that would more effectively support individuals living with FASD across the lifespan; and the research needs for the future. Jury recommendations were documented for each question, with specific recommendations for prevention including: (1) a national primary prevention strategy with a clear message, and education in early school through to post-secondary education; (2) the inclusion of programs targeting social determinants of health; (3) program designs based on evaluation; (4) and programs that are community and culturally driven (Institute of Health Economics 2009, pp. 22–23). The consensus statement which evolved from this event is described as ‘a useful guide to policy and decision makers in order to provide effective prevention programs, treatment, and supports for people affected by FASD’ (Institute of Health Economics 2009, pp. 135–137).

Two comprehensive Canadian publications made notable contributions to the understanding of FASD. The stand-out feature of both books is the contributors, who read like a ‘who’s who’ in the global FASD arena. The first publication is *Fetal Alcohol Spectrum Disorder: Management and Policy Perspectives*, a compilation of the work of experts aimed at health policymakers. In addition to providing a concise overview of prenatal alcohol exposure, FAS and FASD, this book covers topics like the incidence, prevalence and economic cost of the problem; the situation in Canada and

implications for prevention; causes and diagnosis; prevention and a women's health perspective; disability and social supports for adults in corrective services; the impact on individuals and families; responsibility and policy perspectives; and research. Importantly, personal accounts by adults who live with FASD are included (Riley et al. 2011, pp. 413–433).

The second publication, *Prevention of Fetal Alcohol Spectrum Disorder FASD: Who is Responsible?* (Clarren, Salmon & Jonsson 2011) specifically focuses on research and the effectiveness of prevention strategies. In the preface the editors speak of the 'thousands of children' born each year 'with permanent brain injury resulting from exposure to alcohol during gestation' and the 'forceful, determined and sustainable effort' to prevent FASD (p. x). The opening chapter refers to the burden of responsibility placed on women and argues that investment only in pregnant women has been 'misguided, ineffective and punitive' (p.7). The authors suggest that many others share in the responsibility for FASD, including men who perpetrate violence on their partners or drink with them; social determinants such as poverty, poor housing and nutrition; health and social services providers who fail to ask women about alcohol use or fail to offer appropriate support; and governments that inadequately fund 'the programs, services, and infrastructure necessary for providers to reach families who are struggling' (p. 7).

The Fifth International FASD Conference was held in Vancouver in 2013. Attended by international delegates, these particular set of bi-annual conference events claim to bring together 'people who are passionate about this area of work and have provided a stimulating environment for them to make new connections and partnerships' (Interprofessional Continuing Education 2013). In September of that same year the first International Prevention Conference was held in Edmonton, Canada (Institute of Health Economics, Alberta), attended by '700 people from 35 countries worldwide, including senior government officials, scholars and policymakers, clinicians and other front-line service providers, parents, families, and Indigenous people'. The documented outcomes were circulated in draft form to all delegates in late 2013 for comment (Institute of health Economics 2013) and signed off in February 2014 (Jonsson et al. 2014). A highlight of the first International Prevention Conference was a plenary presentation by Professor Stirling Clarren, who reflected on many challenges in the field of FASD. He remarked on the absence of change in the range of abnormalities within the FASD condition since 1978 and agreement on the name, noting that alcohol 'hurts the brain and most tissues in the body'. He reminded delegates of the role of research as the evidence behind the human stories, and the continual need to evaluate what is being done and what is not working. As an accurate diagnosis influences therapeutic interventions and expands surveillance capacity, prevalence rates can be determined. Everything therefore is reported to flow from 'proper diagnosis' which is made accessible for any individual at any stage in their lifespan and is supported by follow-up. Clarren commented on the incidence of FAS, estimated to currently affect from between 1-3 per 1,000 individuals but proposed

this could be as high as 6 per 1,000. In estimating the complete spectrum of FASD, this could be ten times higher. Clarren noted the economic cost estimate of between \$1 million to \$3 million per person and made the point that this cost seemed to gather ‘no traction with government’.

According to Clarren, there are forty-four diagnostic clinics in Canada. Demand is based on client numbers, but the number of estimated cases of FASD in Canada does not equate with the static number of cases presenting for assessment and diagnosis. This conundrum is suggestive of a range of inhibitory factors including distance and accessibility, referral processes, fear of the diagnosis or the name and alcohol as the causal factor, and a mismatch between the services offered and those actually needed. Birth parents’ fear in disclosing their concern is of public stigma and the poor life outcome perceived to be associated with the condition¹¹.

6.5. DIAGNOSIS AND MANAGEMENT, PREVALENCE AND COST

As early as 2001, Dr Margaret Clarke had written a comprehensive document on the prevention, diagnosis and management of FAS, stressing the important role of the primary care physician, strategies of systematic screening of all pregnant women, and timely interventions. She wrote about the cluster of minor facial abnormalities ‘specific to alcohol exposure on Day 20 post conception’ and noted that the absence of facial features associated with a definitive history of fetal alcohol exposure meant another diagnosis ‘needs to be explored’ (2001, pp. 67–75). By 2005 a subcommittee of the Public Health Agency of Canada’s National Advisory Committee on Fetal Alcohol Spectrum Disorder had reviewed and clarified the use of current diagnostic systems (the 4-digit diagnostic code and the Institute of Medicine diagnostic criteria) for the development of FASD diagnostic guidelines for Canadians of all ages and consultation of expert practitioners and partners in the field (Chudley et al. 2005, p. 2). The accommodation of all ages for assessment and diagnosis set a global precedent.

The guidelines were organised into seven categories: screening and referral; the physical examination and differential diagnosis; neurobehavioural assessment; treatment and management; maternal alcohol use in pregnancy; and diagnostic criteria across the spectrum. The diagnostic process was described as optimal when undertaken by a multidisciplinary core team: a case coordinator, a physician trained in FASD diagnosis, a psychologist, an occupational therapist and a speech-language therapist as necessary team members. Screening was stressed as not equating to diagnosis; its importance was aimed at determining whether a pattern of learning and behavioural problems might be related to fetal alcohol exposure. This was proposed as a process which could be undertaken in the education system,

¹¹ Personal notes recorded at the First International FASD Prevention Conference, Edmonton, 2013.

the mental health system, the judicial system or social services, followed by a referral for diagnosis and, for birth mothers, a referral for support. Funding for development, training and maintenance of multidisciplinary diagnostic teams was recommended as necessary to strengthen the service provider capacity (Chudley et al. 2005, p. 3).

In the same year, the Correctional Services of Canada published a report on FAS and its implications for the criminal justice system. Central themes in the report were the implications of FAS/FAE on crime across the lifespan, and the predictors of inattention, hyperactivity, impulsivity, low intelligence, poor school achievement, antisocial behaviour and poor parental child-rearing (Boland et al. 1997, p. 3). The likelihood that individuals affected by fetal alcohol exposure would come into contact with the criminal justice system was considered, and recommendations made proposing pre-sentence screening and the appointment of advocates to support the development and application of appropriate individual need-based programs complemented by in-service training.

A three-year project demonstrated the work of National and Regional Project Advisory Committees on FAS/FAE, collaborations of parents and caregivers, community organisation representatives and Victorian Order of Nurses, Canada staff and consultants. Known as the Von Report, the publication 'Parenting Guidelines for Families of Children with FAS/FAE' was released in 2006 (Victorian Order of Nurses for Canada 2006) and funded by the Public Health Agency of Canada. The guidelines are organised according to strategies: routine and consistency, behaviour management, school and learning, socialisation, diagnosis, secondary effects, support for adult children, connecting with others, care for the caregiver and respite, and advocacy with professions, school systems and the public.

In 1995 the estimated cost of FAS/FAE at \$1.5m per child in British Columbia was tabled, as was a Health Canada prevalence estimate for FAS of two per 1000, with rates as high as 30–40 per cent in some population groups. There was a further call for labelling, a proposal that 'reactivated something that began in 1988 but kind of got derailed in the last few years' (Canadian Parliamentary Proceedings 1995). Conflict of opinion over labelling alcohol beverages created a stalemate in 1996 and again in 2005. Then Hutson (2006, p. 1–4) published a perspective on prenatal exposure to alcohol and the annual cost of substance abuse in Canada, advising that the Canadian Centre for Substance Abuse estimate of nearly \$40 billion did not consider the economic cost of alcohol and other substance use in pregnancy. Hutson argued that the absence of national prevalence data was a factor in estimating the cost of FAS/FAE and proposed that the development of 'objective biomarkers' (p. 2) for prenatal substance exposure presented an opportunity to build prevalence data for Canada. By improving prevalence data and cost estimations, Hutson argued, public policy change might be realised (p. 3).

In recognition of the experience of children living with FASD and the importance of improving outcomes, the Public Health Agency of Canada funded research to examine the relationship between

prenatal exposure to alcohol and tobacco and developmental outcomes in young children. Five hundred children born in 1994 and living in disadvantage in Ontario were recruited to provide longitudinal data. Children of higher-risk parents who self-reported alcohol use during pregnancy ‘showed long-term negative outcomes in measures of school performance and behaviour problems’, and their disadvantages had increased ‘by 10 percent from 4 to 8 years of age’ (Parker 2011, p. 4).

At a national level, the Public Health Agency of Canada reported on the National Roundtable on the Development of a Canadian Model for Calculating the Economic Cost Impact of FASD (Public Health Agency of Canada 2007). The prevalence of FASD in Canada, the limited capacity of diagnostic clinics to meet demand, and the difficulty in diagnosing the neurodevelopmental part of the fetal alcohol spectrum led to the challenge of developing a National Screening Tool Kit for Children and Youth Identified and Potentially Affected by Fetal Alcohol Spectrum Disorder (FASD). The initiative began in 2007. Described as ‘a work in progress’, it was cognisant of the need to account for both sensitivity and specificity and, when justified, to refer for a comprehensive diagnosis where a screening was positive for FASD. Tools considered for trial included a neurobehavioural screening tool, meconium testing tool, maternal drinking guide, medicine wheel tools and FASD screening and referral form for youth probation officers tool. A six-part webinar series introduced the tools to participants, who were able to discuss them with experts (Canadian Association of Paediatric Child Health Centre 2011).

In 2015 revised diagnostic guidelines were released, updated with new evidence that had emerged in the previous decade. A review committee of 14 experts formed in 2012 included four psychologists, three researchers, three paediatricians, one social worker, one clinical geneticist, one FASD clinic coordinator and one parent of an individual living with FASD. Surveys and community consultations were undertaken to gather input; but it is noted that this did not include parents.

The updated guidelines launched in late 2015 adopt the use of FASD as a diagnostic term encompassing all conditions previously included in the fetal alcohol spectrum; specific considerations are explained in the diagnostic assessment of infants and younger children, and for adults. Growth is removed as a criterion and importantly, a new category is included for individuals who do not meet the diagnostic criteria but are determined to be at risk. In respect to brain domains, new terminology is introduced and clarified to include ‘affect regulation’ and ‘executive functioning’ (Cook et al. 2015). Overall, FASD as a diagnosis now shifts the paediatric focus of previous guidelines and is more aware of the impact across the lifespan.

6.6. FOCUS ON SOME WOMEN

In the human services before 1994 ‘there were small bits of new information surfacing that began to describe the effects on developing fetuses of maternal alcohol consumption during pregnancy’ (Lakeland Network, 2012). A FASD Committee was operating in Lakeland, Alberta by 1994, with the aim of building understanding and raising awareness in the region. Using creative activities, its centre targeted as many women as possible, as it was deemed crucial that politicians became aware of ‘the issues and solutions ... at a local, provincial and national’ level; if politicians were not interested, the backstop strategy was to ‘target their spouses’ (McFarlane 2013, personal communication).

In the 1990s, notes Badry (2009) ‘it was common practice for child welfare to be notified by someone from the community or health profession about a mother who was pregnant and using alcohol alone or in combination with drugs throughout the pregnancy’. Prenatal care was reported as lacking, and some mothers birthed their children without ever having accessed any prenatal care. Spouses might ease the mother’s discomfort by bringing alcohol to her bedside, and chaos, tension and challenges could result in police involvement. Mothers who had exposed a previous child to alcohol during their pregnancy might hide the next pregnancy from the scrutiny of child welfare, fearing child apprehension or removal of the child from the mother’s care (Badry 1990).

Women were the core target group of the Sheway project established in 1993. This was a holistic service for pregnant and parenting women in downtown East Vancouver. Sheway recognised that the health of women is linked to the conditions of their lives and to their ability to influence those conditions. The project reached out to pregnant women to assist them in meeting their needs for support, safe living conditions, economic security and physical well-being. Staff members worked closely with women to help them develop the information, skills and confidence needed to care for themselves and their children, affirming the right of all women to self-determination within their own cultural, spiritual and social context. Sheway planning documents (unpublished) confirm that Sheway endeavoured to link its program with those in the community who shared these goals (Poole 2000, p. 5). Sheway continues to deliver services in the same holistic way 20 and more years later.

A report by Loock et al. (1993) documented poor health outcomes for many mothers and their children. Some forty per cent of infants born over a two-year period ‘were exposed to alcohol or other drugs in utero’; 33 per cent of the exposed infants had low birth weight, and all of this group of children ‘were apprehended by child protection authorities’. The report noted the increasing number of ‘socially high risk pregnant women with substance use problems’ prepared to birth their babies ‘with no history of prenatal care’. The findings from the report motivated ‘a proposal for the development of a community-based integrated service that would meet the complex health and social needs of this population of women and children’, aimed at reducing the potential harmful effects of prenatal drug

and alcohol exposure by providing a community-based continuum of outreach education and service to women at risk (in Poole 2000, p. 2).

The Canada NW FASD Partnership has supported the work of a Network Action Team on FASD prevention from a women's health perspective since 2005. This Network Action Team focuses on ensuring that social determinants of health are at the core of all prevention efforts, with understanding and action on those factors 'that increase, or reduce, women's risks for developing substance use problems and having a child with FASD'. Such a focus 'requires collaborative action among women, service providers, policy makers, researchers, and the communities who are affected' (British Columbia Centre of Excellence for Women's Health 2013).

Between 1996 and 1998, Nancy Poole and Roland John Bennett revised available reference materials and, with contributing authors, wrote *A Community Action Guide* (Poole & Bennett, 1998). Even at this early stage a complete section highlighted alcohol use by women and identified many of the psycho-social and environmental influences on women's lives (pp. 39–53). As the authors note, denial of a drinking problem can be exacerbated by 'the fear of negative societal attitudes towards women who have alcohol and drug problems; fear of losing children if she acknowledges having a problem, and fear of leaving children in someone's care while getting treatment; guilt and shame – for having a problem, for not being a "good mother," for not being perfect, etc'. (p. 47).

Health Canada (1996) released a joint statement on FAS and FAE with seventeen co-signatory organisations, to provide 'relevant and factual information to guide health care professionals in the treatment or counselling of women, their partners and families with respect to alcohol intake during pregnancy'. It acknowledged the broad-based efforts required in 'effectively dealing with the problem' (Canadian Paediatric Society 1996). Primary, secondary and tertiary prevention were distinguished, with recommended actions grouped accordingly: (i) avert a health problem, (ii) identify persons at risk, and (iii) prevent recurrence through treatment and support. In this latter case, special attention was given to women and partners who already had a child diagnosed with FAS/FAE and who planned subsequent pregnancies.

This occurred in the same year that Habbick et al. (1996, pp. 204–207) reported an unchanged incidence of FAS in Canada in 20 years. Nevertheless, recommendations continued to target women in their childbearing years and those who influenced them, including their partners. There was an emphasis on strategies as 'family-centred and culturally sensitive ... in the context of their community; and comprehensive, to draw on all services appropriate to the often complex social, economic and emotional needs of these women' (Health Canada 1996, p. 5). The joint statement also focused on health professionals as having a key role in identifying women 'at high risk for heavy alcohol consumption before and during pregnancy' as well as on the importance of providing

information and continuing education to health professionals. Alcohol and drug treatment programs were encouraged to 'incorporate the needs of women' in their design and to prioritise pregnant women seeking addiction treatment (Health Canada 1996, p. 6).

In February 1999, expanded funding of \$3.8 million was granted to the Canada Prenatal Nutrition Program to enhance 'FAS/FAE initiatives in First Nations and Inuit communities', particularly to identify gaps in services, 'build on strengths and new opportunities' and collaborate with the Assembly of First Nations and Inuit Tapirisat of Canada (Health Canada Update, 2000). A press release in the same year announced a National Advisory Committee of 18 members, including representation from First nation and Inuit people: there was an expressed mandate to 'ensure that people affected by FAS/FAE have a voice in the committee's work'. The Committee would advise and bring expertise to Health Canada on related issue and give 'priority attention to the Budget 1999 commitment' (Blondin 2000).

Thom (1997) explored the presentation of women as a 'risk group' and claimed that historically, 'women's drinking was linked to major issues of national well-being and women were allocated a central role in securing a healthy population'. In the 1970s, Thom argued, the issue of women's drinking shifted from a 'good of the nation' paradigm to a feminist perspective on women's health. This shift located harmful drinking primarily within a social and economical context' (p. 47). Thom also argued that 'the new feminism of the 1960s ... challenged existing orthodoxies on women's health status and the quality of health care they received'. This 'placed women's health issues in a political context' and changed notions of the problem from 'alcoholism' to 'problem drinking,' merged developments in research and service provision and alerted international attention to women's drinking (p. 38). Women's drinking seemed to enter the political discourse, he noted, 'when it symbolises the threat of changing gender relations'; and it seemed unlikely 'that the scientistically erected status of "high-risk" group will result in policies which respond to the association between alcohol problems and gender-related needs' (MacDonald 1997, pp. 48–49).

In the final year of the century, 'Substance Use and Pregnancy: Conceiving Women in the Policy-Making Process' was published by Rutman et al. (2000). This paper proposed alternative ways to address the problem of FAS that were 'less poisoning and punitive' towards women, and required ideological shifts from a moralising/medical model to a harm reduction/health promotion approach; from a child welfare mandate seen as protective to a greater emphasis on supporting families; from viewing child apprehension as a failure of the mother to seeing it as a failure of the system and of communities to provide what was needed.

Barriers for women were identified as the fear of child apprehension; contradictions between recommended abstinence and harm reduction approaches; contradictions between addictions

(sickness) and child protection ideologies; lack of fit between existing treatment options and pregnant women's needs; inflexible rules and inaccessible care; unsupportive attitudes of practitioners; lack of training of practitioners who could help; and a lack of resources to enable women to access treatment. Attitudes and understanding of the nature of the problem were influenced by similar discourses – scientific, medical experts, media, and legislators and politicians:

Children in care with FASD are as good as we are. It's our job to explain who they are to the world, not their job to explain their world to everyone (Badry 2013, p. 7).

The publication of 'Prevention of Fetal Alcohol Syndrome' as a guide for physicians, midwives and other health care professionals recommended a consistent message: 'the prudent choice is to abstain from alcohol' (Alberta Partnership on Fetal Alcohol Syndrome; 1999). While information still tended to target higher-risk drinking women, the aim was to spread awareness among women of small amounts of alcohol equating to minimal risk and the benefit of reducing or stopping alcohol use at any time to reduce harmful effects and to make them aware of the increased risk of FAS in subsequent birth children for parents who already had a child with FAS.

To support the initiative, the government of Alberta announced a grant to the Alberta Partnership on Fetal Alcohol Syndrome of approximately \$7 million in 2000. The aim was to 'enhance regional projects such as early identification of fetal alcohol children, public awareness campaigns and training for professionals who work with mothers consuming alcohol while pregnant' (Alberta Government 2000). The Alberta Partnership was predecessor to the Alberta FASD Cross-Ministry Committee and focused on 'developing and delivering community-based solutions, making it easier for those affected by FASD to get the help they need, at any point during their life' (Alberta FASD Cross-Ministry Committee, 2011).

Nancy Poole published a paper on the current status of FASD programs that had a child-centered focus and a single determinant, alcohol. Poole argued that a broader approach would help reduce barriers for women who need help and proposed the implementation of 'evidence based policy and programs that address the multiple determinants of women's drinking' which would also require true representation by women on Health Canada's National Advisory Committee; prevention strategies to improve women's health needs should also be included. Poole proposed three levels of prevention that needed to be implemented: (1) raising public awareness to build greater understanding of the causal factors in women's substance use problems, thereby changing negative attitudes towards women and reducing inequalities in their health status; (2) focusing on systematic care for women and targeting all health service providers; and (3) building a constellation of services to overcome the 'pervasive, systemic unwillingness to reduce barriers to access' (Poole 2003, pp. 7–9).

Tait's (2003) post-graduate thesis considered the bias that positioned FASD as a problem primarily affecting First Nation women and their children: a bias reinforced by research and claims from FAS advocacy groups that led to targeting Aboriginal populations in cities and reserves. Research, clinical practice and public health strategies in Canada had overwhelmingly targeted Aboriginal populations, stressing that FAS affected Aboriginal groups in disproportional numbers. Somewhat related was a research paper published in 2006 which claimed a 'double-speak' constructionist paradox 'between Aboriginal women as "citizen" in dialogue in health policy reform' and their real-life experience as medical clients 'lacking legitimacy' in their engagement with health services, which perpetuated their marginalisation (Fiske & Browne 2006, p. 91).

Health Canada also published a report in 2005 entitled 'Alcohol Use and Pregnancy: An Important Canadian Public Health and Social Issue'. The report highlighted key data on alcohol consumption in pregnancy, including that three quarters of adolescent girls and women in Canada reported having used alcohol in the previous 12 months; 10% reported heavy drinking at least once a month with the rate typically higher among younger women; and 'drinking among school aged females appears to have increased from late 1980s to late 1990s' (Dell and Roberts 2005, p. 12). In the eastern provinces, Dr Gideon Koren reported on the first nine years of a program for early identification and prevention 'for pregnant and parenting women who are using substances and have young children'. An estimated 51.4 per cent of pregnant women were using alcohol at program intake, it was estimated (Koren 2004). A conference held in Ontario in the same year considered improving women's health and the prevention of FASD from the perspective of policy development. It focused on indicated prevention, 'directed at the care of pregnant women who have significant alcohol problems or addictions, and who require more than information, advice or brief interventions in order to change their alcohol use in pregnancy' (Sarkar et al. 2006, p. 1). Recommendations from policy stream of the conference included treatment protocols for those women with co-morbid addictions and mental health issues, the promotion of outreach services for women, post-rescue advocacy and care programs for women escaping intimate partner violence, and training for frontline workers in identifying and honouring the key relationships in women's lives (Sarkar et al. 2006, pp. 11–12). At the same time, results from the Canadian national survey regarding knowledge and attitudes of health professionals led to recommendations including the screening of all 'pregnant and post-partum women' for alcohol use 'by relevant health care providers'; the message recommended for women was abstinence.

As previously mentioned, in 2006 the Canada Northwest FASD Research Network selected the British Columbia Centre of Excellence for Women's Health to form one of five Network Action Teams with a 'focus on women's health issues in the prevention of FASD' (CanFASD Research Network 2013). Nancy Poole and Amy Salmon, 'significant leaders, particularly in relation to prevention', co-led the team. According to information on the website, the team meets monthly using videoconferencing, with

a virtual community of practice approach which enables practice development through shared experiences, information and resources, problem solving and developments, on-site visits and mapping gaps. 'We also try to hold an annual face-to-face meeting linked to a conference on FASD related issues' (CanFASD Research Network 2013). The five Network Action Teams held three forums in 2006 to examine a range of related areas, including the gathering, storage, access and use of cross-jurisdictional data on women's alcohol use. Other considerations included what research information was needed on best practices, in health promotion with women, prevention, messaging, community awareness activities and other strategies to prevent FASD; what research was needed on best practices in screening and brief intervention with women of childbearing age; what research information was needed to support best practices in working with women at highest risk of having a child affected with FAS; and how best to reduce barriers to care (CanFASD Partnership 2013).

By October 2007 the Network Action Team on FASD Prevention from a Women's Health Determinants Perspective had prepared an information sheet on system-level, program-level, and personal and social barriers that affected the ability of programs and services for women to develop linkages, hindered a woman's ability to access services and manage care in the community, and affected women's 'ability to identify and benefit from prevention and support services' or to assist with 'making recommendations to policy makers for improving access to care for women' (Network Action Team on FASD Prevention, 2007). A blog was established by 2013 and is now visited by over 2000 people each month. The 'Girls, Women, Alcohol, and Pregnancy' blog 'serves as a space to highlight work by Network Action Team members, provide links to resources and recent research findings, discuss innovative strategies and FASD prevention activities from around the world, and provide critical perspectives on challenges in the field' (British Columbia Centre of Excellence for Women's Health, 2013).

The Alberta Cross Ministry Committee on FASD released the '10 year FASD Strategic Plan for Alberta' in 2006, which was signed off by ten portfolio ministers. As part of the planning process, the FASD-CMC reported the completion of an inventory of current FASD programs and services, identified a group of primary stakeholders and had performed a gap analysis to identify 'major areas for development over the next 10 years' (Alberta FASD Cross Ministry Committee 2008). Meanwhile, the Canadian Standing Committee on Health (2006) tabled *Even One is Too Many: A Call for a Comprehensive Action Plan on Fetal Alcohol Spectrum Disorder* in the House of Commons (Health Canada 2006). In this publication, the Government of Canada is reported as taking 'a holistic, integrated approach to FASD, recognising that FASD is not just a health issue but has long term societal and economic implications'. A pan-Canadian Action Plan was recommended with provinces and territories and stakeholders consulted, the former responsible for service delivery and the latter having overall policy leadership. The committee identified the need to increase public and professional

awareness and understanding of FASD with the agreement that all women are at risk. There was an expressed need for information to be clear, with consistent messages from providers, family and friends and consensus that there was ‘no safe threshold for alcohol when planning or during pregnancy’. It was recommended that resources should be consolidated and guidelines developed for those who are parenting, with a train-the-trainer module for FASD knowledge and intervention skills. Expanded knowledge should be inclusive of (a) the life conditions affecting those with FASD; (b) knowing how to support those affected; (c) understanding the root causes of alcohol use during pregnancy and how to support women; and (d) awareness of the permanent impacts of prenatal exposure to alcohol on children (Health Canada 2006).

The Public Health of Agency of Canada contracted the Best Start Resource Centre to review Canadian awareness campaigns on prenatal exposure to alcohol. From phone surveys, information was gathered on effectiveness, development, design, and sensitive and respectful approaches. The research confirmed that effective campaigns on alcohol in pregnancy ‘follow basic accepted practices’ and should ‘carefully consider and test all aspects of the campaign to ensure that they as respectful and sensitive as possible to women who are struggling with alcohol use and to families affected by FASD’ (Burgoyne 2006, p. 3).

Nancy Poole’s ‘Gender does matter: coalescing on women and substance use’ (2007) brought greater attention to ‘research on how gender affects all aspects of substance use, addiction and women’s health and women’s needs and access to resources and treatment,’ the interconnection of substance use with other issues experienced by girls and women such as trauma and mothering; helping violence and sexual assault centres and related mental health services integrate knowledge on substance use into their settings, the need for a woman-centred approach in which barriers linked to broad determinants of health are addressed through ‘a multi-level, multi-sectoral response’ based on ‘collaborative action that includes women, service providers, policy makers and researchers’, and the development of a didactic approach in working with the ‘mother-child’ unit’ (p. 8). The document was aimed at helping addiction services

integrate work on trauma, provide information on the connections with addiction recovery and offer individual and group programs. Women who have sought help for trauma and mental health issues report misdiagnosis, medication over-prescription and re-traumatisation through encounters with health care providers who are not sensitive to their needs. (p. 8)

According to Poole, ‘a gap remains between what we know and what we do’ (p. 8). No one wants to put children at risk, Dr Rubeena Ahmad added (in Sinneme, 2008), but if mothers can get the necessary support ‘through the treatments of their addictions, treatment for their mental illness,

making sure they got food in their bellies, making sure they didn't have to work the streets to get food and a fix, and a roof over their head, then they have a chance of keeping their kids'.

Girls' and women's use of alcohol highlights gendered experiences of pathways to substance use as 'sexual and physical abuse and trauma ... the greater impact (demonstrated by research) on women of life transitions, and their greater use of substances to cope with emotional and relational problems' (Greaves & Poole 2008b, pp. 1–2). Prior to 1970,

there were fewer than 40 published studies on women and substance use (excluding tobacco use) ... however, as part of the 'second wave' of the women's movement, agencies and practices began to emerge that focused on providing a feminist response to the issues of substance use for women. Compounding these risks are the gendered marketing practices of the alcohol and tobacco industries, and the societal stigma carried by women – especially pregnant women and mothers – who use substances, which creates enormous barriers to care. (Greaves & Poole 2008b, pp. 1–2)

In the same year Badry (2008) submitted a post-doctoral thesis, 'Becoming a Birth Mother of a Child with Fetal Alcohol Syndrome' multiple strategies for FASD prevention within a four-part framework for promoting 'women's and children's health' was determined by Canadian experts. The Framework called 'FASD Prevention: Canadian Perspectives' resulted from conversations with service providers across Canada. It reflects the prevention of FASD and aims at 'improving the outcomes for those who are already living with it' (Poole 2008, p. 2). One of the major contributions is the expansion of the levels of prevention from three to four, to include the prevention of future exposed pregnancies through support in the post-partum period. In recognising the complexity of FASD prevention work, this document highlights the need to address and help women heal from many of the 'root causes of addiction' to improve their health and so reduce the risk of an alcohol- exposed pregnancy.

Level 1 is focused on raising public awareness with health promotion activities supportive of girls' and women's overall health and engaging communities to 'promote social support and social change'. Level 2 concerns building 'service provider confidence' to promote 'safe discussion of pregnancy, alcohol use, and related issues' with individual girls' and women's social networks and preferred healthcare providers. Level 3 is about ensuring specialised, culturally specific and accessible 'recovery and support services' for women experiencing alcohol use issues and mental health concerns, which are to be made available throughout the childbearing years. Level 4 covers the post-partum period to support new mothers, whether or not they have been able to make positive changes 'in their substance use during pregnancy'. A multi-faceted approach ensures mothers have access to the necessary supports to 'continue to improve their health ... as well as the health of their children' (Poole 2008, p. 3).

Lawryk's (2009) 'Interviewing Women Regarding Substance Use in Pregnancy' addresses the lack of standards and inconsistencies in interviewing women about their use of alcohol and other substances in pregnancy, and to counter screening tools that are 'intimidating.' A year later, the August edition of the *Journal of Obstetrics and Gynaecology* (2010) was devoted to the endorsed 'established national standards of care for the screening and recording of alcohol use and counseling on alcohol use of women of child-bearing age and pregnant women based on the most up-to-date evidence' (Rowe 2010). The guidelines acknowledge evidence of alcohol and fetal harm with 'insufficient evidence of a threshold for low-level drinking', abstinence as 'the prudent choice for a woman who might become pregnant', and culture- and gender -appropriate interventions (Rowe 2010, p. 1). The guidelines also recommend universal screening, the offering of safe environments for women to 'report alcohol consumption', screening as part of 'routine women's health care', brief interventions and the encouragement of harm reduction/treatment strategies if drinking continues in pregnancy, priority access for pregnant women 'to withdrawal management and treatment' and advice that 'low-level consumption of alcohol in early pregnancy is not an indication for termination of pregnancy' (Rowe 2010, p. 1).

In another 2010 event, a meeting of a working session of the Network Action Team from the perspective of a women's health determinants (Canada Northwest FASD Research Network 2010) reached consensus on the components of FASD prevention: they were to be respectful, relational, self-determining, women-centred, harm reduction oriented, trauma-informed, health promoting, culturally safe, supportive of mothering, and accounting for the possibility that women with substance use and mental health problems are also living lives affected by disability. *Women and Alcohol* (British Columbia Centre of Excellence) was funded by Health Canada to broaden 'the scope of much of the current FASD prevention materials to include alcohol use pre- and post-pregnancy. It examines the impact of alcohol on groups of women and mothers who are often missed by screening, education and treatment'. *A Sensible Guide to Pregnancy* (Health Canada 2011) is a resource in which the topic of alcohol and pregnancy is inclusive to a range of health issues for pregnant women.

The Children's Mental Health Research Quarterly (2011) is a Canadian newsletter which aims to connect research and policy 'to improve children's social and emotional well-being [by] addressing the determinants of health; preventing disorders in children at risk; promoting effective treatments for children with disorders; and monitoring outcomes for all children'. An article in this publication offered a systematic review of four brief intervention programs; the researchers suggested (a) 'most women stop drinking during pregnancy ... whether or not they received the intervention' and (b) 'women at highest risk may gain the most from preventative interventions' (Swartz et al. 2011, p. 1).

Amy Salmon was one of the contributing authors and at the time, co-ordinator at Sheway. Salmon wrote that social problems and alcohol use were 'inexorably linked to the conditions in which [women

and children] live’: that shame and blame are often barriers to care, and that prevention messages must be accompanied by community supports ‘that make staying away from alcohol both feasible and safe’. Salmon raised the issues of mothers who are themselves affected by FASD, and of marginalised women who often have few life choices. Most have not completed high school, almost all have experienced physical or sexual abuse, and almost all have mental health problems including substance misuse. Salmon questioned if increasing public awareness will lead to some women not disclosing substance use because of perceived judgment or fear of the removal of children from their care (Children’s Mental Health Research Quarterly 2011, pp. 10–11).

At the close of 2013, Eggerston (2013) wrote about the findings in a report from the Canadian Centre for Substance Abuse ‘Licit and Illicit Drug Use During Pregnancy: Maternal, Neonatal and Early Childhood Consequences’ and challenged doctors and health providers ‘to check their moral outrage’ and instead treat pregnant women who are dependent on drugs with compassion and support. The author cites Finnegan (2013) who points out that stigmatisation remains ‘one of the biggest barriers to effective treatment for pregnant women who use legal or illegal substances’ and also noted that this was at odds with women’s use of alcohol and other drugs which is claimed as ‘a burgeoning epidemic throughout the world’ (Eggerston, 2013).

6.7. FOCUS ON ABORIGINAL COMMUNITIES

Close examination of the rooted structural issues of history, racism, and social and economic frameworks that create disadvantages for Aboriginal women in Canada has led to the creation of a dominant discourse that suggests FASD is an Aboriginal issue, and that blames mothers and holds them, as individuals, responsible for maternal health and birth outcomes. These points are contested by many Canadian women authors (Badry 2012; Hunting & Browne 2012; Poole 2007; Poole & Greaves 2007; Rutman et al. 2000).

In 1997, Health Canada released *It Takes a Community*, a report resulting from a collaboration of FASD experts, provincial and territorial governments, national Aboriginal organisations and First Nation and Inuit community representatives. Session participants stressed the need to address FAS/FAE issues holistically to account for the social determinants of health, including ‘discrimination, poverty, domestic violence, solvent and drug abuse, and residential school

syndrome'¹². Nine years later, the Ontario Federation of Indian Friendship Centres produced a 'FASD Tool Kit for Aboriginal communities' using a 'medicine wheel' to represent a holistic approach to FASD prevention recognising the inclusion of relationship, reason, movement and mobilisation and vision (Wemigwans 2005).

Square in 1997 highlighted the First Nations reserve experience and claimed that '1 in 10 children is the victim of alcohol teratogenesis and that 'for every child identified ... in northern Manitoba, there are probably 2 or 3 others with behavioural and learning problems'. Square reported 'roughly 100 cases of FAS/FAE [per 1000 births] on the reserve' and claimed this prevalence rate meant FAS qualified as an epidemic: 'it is time for federal and provincial governments to take action' (p. 59). FASD was officially understood at this time to be 'a nation-wide health concern' and non-discriminatory 'on the basis of race, socio-economic status, or sex'; it was still presented as 'an alcohol and addiction issue, with ramifications in areas including women's health, disability, family violence, mental health, employment, child welfare, education and criminal justice systems' (Health Canada 1997).

Josephine Nanson (1997, pp. 807–808) considered binge drinking in pregnancy with a focus on identifying women at risk, targeting pregnant women who sought information from Motherisk counselling service in Toronto. Traditional notions of mothering in identifying the stress of pregnancy as a possible reason for alcohol use were challenged, as was traditional research on pregnant women who drink. Nanson cited Square (1997), who had written about socioeconomic status, employment history and education as barriers for women at highest risk who might not contact health services. Square's argument was that these factors had been ignored, and suggested that drinking in pregnancy might be a coping mechanism in response to life trauma, which disrupted their consideration of the risk to their unborn children. Nanson pointed out that Square had also argued for the recognition that women 'rarely wish to harm their children' and proposed 'compassion and support' replace legal solutions which were framed as treatment. Square had also proposed improving the overall health of young, poor women, which she believed should reduce the incidence of alcohol-related birth defects. Nanson claimed there is a need for 'family centered treatment programs in which children are integrated and for multi-faceted, community based prevention programs designed for and by the community in which women at high risk live'. The growing acceptance of women as a 'special group'

¹² Residential schools were a system 'set up by the Canadian government and administered by churches that had the nominal objective of educating Aboriginal children but also the more damaging and equally explicit objectives of indoctrinating them into Euro-Canadian and Christian ways of living and assimilating them into mainstream Canadian society'
<http://indigenousfoundations.arts.ubc.ca/home/government-policy/the-residential-school-system.html>.

led to doubt about the efficacy of current therapeutic approaches to needs of women which arose from traditional gender constructs or from women's social position in relation to men (Nanson, 1997, pp. 807–808).

Halseth (2013) produced a comprehensive appraisal of the health of Canadian Aboriginal women in respect to gender and socio-economic determinants of health as barriers. Racism, violence, poverty, HIV, alienation from community and culture, single motherhood and low rates of educational attainment and employment were 'some of the factors that intersect with gender to impact health and well-being of Aboriginal women' (p.15). The depth of research in this document demonstrates the attention Aboriginal health has received over time; however, Halseth concludes,

The many challenges associated with health status among Aboriginal women in Canada can be largely attributed to historical precedents and the resulting socio-economic circumstances. Addressing these challenges is complex within a multijurisdictional framework of health care provision and within the diverse contexts of Aboriginal women's lives. (2013, p. 15)

Disparities were revealed in a comprehensive comparative review of research conducted on Canadian Aboriginal children in the areas of autism, cerebral palsy and FASD. Of 52 reports published since 1981, 51 focused exclusively on FASD with little attention given to engaging the local communities. The authors concluded that the focus on FASD was not representative of the prevalence of these three conditions and violated 'fundamental principles ensuring equitable representation of all children regardless of background in research and access to benefits of research in health care and [perpetuated] stigma in an already marginalized population' (Di Pietro & Illes 2013, p. 81).

6.8. THE ALCOHOL INDUSTRY

In Canada, the alcohol industry is not self-regulating but, with government, jointly funds the Canadian Centre for Substance Use. Warning labels on alcohol containers, mandated reporting on those diagnosed with FAS, and court-ordered treatment for pregnant women originated in the Yukon; by-laws requiring warning signs at point of sale were established in some communities and key standards and policy directions and the development of a policy document, 'FAS: Collective Action for Collective Solutions', recognised the need for policy change. Single (1993), a director of the Canadian Centre for Substance Abuse and a consultant to the alcohol industry's International Center for Alcohol Policies wrote an opinion piece and argued the bias of policy advocates as the real problem. According to Single, policy advocates must be credible, communicate promptly and clearly, and consider all aspects of an issue. His argument is based on a perception that policy advocates are highly specialised and have technical knowledge but lack the ability to communicate well with the ordinary public; he

noted that the ‘David and Goliath image of public health professionals against a huge alcohol industry may be appealing, but in the long run it is an over-simplification’ (Single, 1993).

In a brief submitted on April 22, 1997 to the House of Commons Standing Committee on Health, the Brewers Association of Canada suggested the Federal Government keep the Canadian Centre on Substance Abuse as the national coordinating body linking federal and provincial efforts on substance abuse issues and concerns. The Brewers Association of Canada proposed the federal government’s role on issues of alcohol misuse should be to foster a public policy environment that encourages rather than discourages health partnerships among all stakeholders. The Brewers Association of Canada argued for ‘a national coordinating body on substance abuse’ taking advantage of the current ‘expertise, credibility, visibility and track record’ of the Canadian Centre on Substance Abuse with ‘no need to reinvent the wheel’ (Brewers Association of Canada 2001). Although the Brewers Association of Canada acknowledged the importance of broader public policies contained in a population health approach to health issues, it stressed that these were no substitute for ongoing, effective, targeted programming. While policymakers may choose to shape the environment so that it reinforces the adoption of moderate drinking practices, the Brewers Association of Canada argued policymakers could not afford to overlook the complementary role of more targeted programming, focused on those at risk. At this time the Brewers Association of Canada, as a founding partner in funding the Fetal Alcohol Resource Centre at the Canadian Centre on Substance Abuse, renewed its commitment to a further year of funding support and reported in their newsletter *On Tap* that it was supplying funds to support additional alcohol and pregnancy warning posters produced by Health Canada for display in Ontario, and that it had been supporting of this kind of initiative since ‘the late 1980s’. The promotional content of the posters included information on the FAS Information Hotline, funded by the Brewers Association of Canada and operated by Motherisk, Ontario (Brewers Association of Canada 2001).

In 2002 Paul Szabo, Member of Parliament for Mississauga South from 1993 to 2011, reported that the alcohol beverage industry had made a profit of \$700 million and spent \$660 million on advertising; Health Canada in that time had invested 3.3 million in FAS. Szabo had been pushing for alcohol beverage labels for ten years when he tabled a private member’s bill, Bill C-206, in 2005. The media reported the labels he proposed were similar to ones found on cigarette packages, warning about the possible effects of alcohol including birth defects: ‘The beverage industry opposes the plan, claiming it would cost up to \$20 million [Canadian dollars] a year to implement. Twenty countries have similar labels, including the United States’ (CBC Online 2005). Szabo defined warning labels as a ‘lighthouse, sending repetitive signals of impending danger’ (2007). Bill C-206 ‘died at committee level’ even though it had been approved in the House of Commons by 225 of 252 votes. Ten members of the alcohol industry were present at the committee meeting and ‘argued that labelling would not

work’ unless part of a comprehensive strategy. Szabo was quoted as suggesting the failure of Bill C-206 was linked to taxation: ‘Every time you take one dollar away from the alcohol industry, various levels of government lose \$4.50’; which offered no incentive to change (Citizen Special 2005). The alcohol industry representatives counter proposed that public awareness about alcohol use in pregnancy and the risks of FASD was ‘very high and that labels were not effective’, and that funding ‘would be better spent on targeted programs’ (Loney et al. 1994, pp. 248–251).

Later in 2005, a motion to require Health Canada to table a comprehensive strategy to address FASD passed with the support of all parties. Mr Rob Merrifield (Member of Parliament for Yellowhead) stated:

[We do not need] more studies ... or consultation. We ... need to do something about it and Health Canada can do something about it ... to move to action ... It is something that needs to be done because failure to do it means that we will do nothing. Doing nothing on this issue is not appropriate ... We did hear from the alcohol industry ... It would cost a significant amount of dollars and dollars are not going to come out of thin air ... they can come out of either the consumers who use it or the already existing programs that deal with fetal alcohol syndrome disorder ... a paradigm shift ... Peer pressure is a powerful thing (Alcohol Policy Network 2005).

6.9. SUMMARY

The Canadian story began with diverse stakeholders in collaboration: parents, interested medical professionals and politicians, championing the cause because they had knowledge through shared clinical practices or had a personal stake. Collaboration was seen as critically important, involving women’s health, medicine and public health, who with a shared vision, created key policy documents considerate of gender. In the research arena, the NW FASD Partnership created network action teams reliant on collaborations with a clear agenda on research from the perspective of the social determinants of women’s health. The innovative Canadian response to FASD was mobilised by powerfully persuasive women researchers who from the 1990s lobbied for FASD programs and interventions to take a didactic approach and recognise that preventing FASD means addressing holistically the life experiences of high-risk women who struggle with multiple issues. However, progress such as the higher availability of clinical services has not translated into higher numbers of people taking advantage of them. Accessibility in a remote country, or continued fear of the cause, diagnosis or stigma, have been suggested as possible reasons for this. If the Canadian experience is fraught with obstacles, what does this mean for Australia?

CHAPTER 7 FASD IN AUSTRALIA

In Australia, unlike the United States and Canada, the overlap between FAS and FASD means they cannot be easily separated, and this has influenced public policy agenda-building. Some medical knowledge of FAS did not match the limited medical understanding of FASD, and there was hesitancy to diagnose; this coloured the attitudes of policy-makers who relied on the medical profession for guidance. Over three decades, the originators of demands continually had to find new ways to engage policy attention. In 1999 adoptive parent, proponent and key advocate Sue Miers mobilised a small group in South Australia that would become known as the National Association for Fetal Alcohol Syndrome and Related Disorders (NOFASD Australia). Disillusioned by the lack of available Australian knowledge, understanding and support at the time, Miers travelled to Canada and reported on her Australian experiences at the 1999 Prairie Province Conference on Fetal Alcohol Syndrome:

The establishment of NOFASD AUSTRALIA as a network of people with interest in FASD and the national distribution of a report including our families experience ... [emerged from] ... a comparison between information and understanding of FAS in Canada with the apparent lack of information and acknowledgement of FAS in Australia. (Miers 2013)

In Miers' 1999 report several recommendations were made, including an urgent call for 'Australian based research to encourage informed discussion about FAS and identify areas of need' and for collaboration between engaged parties from education, diagnosis, intervention, care and support. Miers called for the immediate establishment of a working party to advance diagnosis, prevention and intervention, and for the urgent dissemination of 'clear, accurate, complete and consistent information on FAS'. She called on the South Australian Medical Association to ensure that doctors had the necessary knowledge, skills and tools to screen women and provide accurate information to them, and recommended a public forum be held with invited experts to raise public awareness. She recommended the production of videos for the public and for service providers. The final recommendations in the report concerned the alcohol industry: Miers proposed a partnership with the South Australian Medical Association be formed to acquire funding to promote safe drinking and to pursue labelling on alcohol beverages (p. 35).

This same report led to a meeting between Miers and South Australian geneticist Professor Eric Haan, who asked Miers write the foreword to the SA Birth Defects Register highlighting her family's experience. Professor Haan shared the information with members of the Australian Paediatric Surveillance Unit including Professor Carol Bower and Professor Elizabeth Elliott, both of whom became recognised experts on FASD in Australia.

There was information available at the time, as was clear when Dr Nicholas Williams, a South Australian doctor who had been practising medicine for over 30 years, presented a paper on FAS to the Best Practice Interventions in Corrections for Indigenous People Conference (1999) in Adelaide. Williams had worked in Canada, and in his presentation provided information on alcohol teratogenicity, the mechanisms of alcohol and the breakdown product of acetaldehyde, the reduced flow of oxygen and prostaglandin imbalance, the continuation of effects throughout gestation, and the failure to identify any safe dose of alcohol during pregnancy. He spoke about diagnostic criteria based on 1996 US Institute of Medicine standard criteria, North American estimates of cost, and the potential adverse effects of fetal alcohol exposure; and advised that ‘FAS makes up only a small part of Foetal Alcohol Effects (FAE). This term refers to all the effects caused by prenatal exposure to alcohol’. Williams noted the lifetime impact of fetal alcohol exposure, including what he termed ‘behavior problems’ as uninhibited and impulsive and failing ‘to consider the consequences of action’. He also made reference to secondary disabilities, and the connection between FAS and involvement in crime (Williams 1999, p. 2).

7.1. DEMAND FOR ATTENTION 2000–2005

NOFASD Australia struggled to attract attention, and had gained no government funding despite an ever-increasing need expressed by families. FASD was not a registered disability in Australia, and there was no Medicare rebate for its diagnosis. No clinical guidelines for diagnosing FASD had been developed, and there were no specially trained multidisciplinary teams. In this first decade of the century, there was more chance of Australian stakeholders meeting at one of the international conferences held in British Columbia than in Australia.

In the first year of the new millennium, Miers (2000) was invited to make a presentation to the Australian Commonwealth Government’s Standing Committee on Family and Community Affairs. Her advice was that ‘any inquiry into the social and economic costs of substance abuse cannot ignore the impact of Fetal alcohol spectrum disorders [sic], especially with regard to family relationships, crime, violence, law enforcement and health care costs’. Later Miers’ likened her presentation to a ‘personal grilling’ which seemed ‘more like a court room cross examination’. The decision of the Committee was to refer the matter to the Australian Medical Association for further clarification.¹³ Miers could not have realised at the time that this referral, to those perceived to have the technical

¹³ Personal communication in 2010, during which Sue Miers reflected on her presentation to the Standing Committee on Family and Community Affairs, December 2000.

authority to advise government, would determine the manner in which FASD policy would later be managed.

Elizabeth Tindle, a psychologist, wrote a paper aimed at addressing education, health, and the financial and social impacts of fetal alcohol exposure in children, young people and adults (2002). Anne Russell, a birth mother who had joined the NOFASD network, was perhaps the first birth parent to speak publicly of her experience. Russell attended the 2002 Prairie Northern Conference in the Yukon, Canada, and reported back on the critical need for diagnosis and interventions for children living with the effects of fetal alcohol exposure and the implications for children in the absence of specialised services (2002, p. 8). Just as her contemporary, Sue Miers, had reported three years earlier, Russell outlined a set of recommendations calling on the Australian federal and state governments to implement public awareness campaigns, school-based education on FAS, and ‘early recognition and treatment for at-risk women and culturally-centred programs’ (2002, p. 36). Russell recommended that a clear message frame all FAS prevention resources: ‘no alcohol is the safest choice for a healthy pregnancy’. She proposed surveillance of alcohol-exposed pregnancies and outcomes ‘in order to capture the true incidence of FASD’ and recommended all alcoholic beverages carry health warning labels. The Australian Medical Association was urged to update its clinical practice guidelines and deliver education and training, and particularly to familiarise their profession with screening tools. The final recommendation required that all recommendations in the Fitzgerald Report (2001) be implemented, including a foundation based ‘on a Canadian model [and] that health and justice issues should be addressed by the empowerment of local communities’ (Russell 2002).

7.2. THE CASE FOR AN AUSTRALIAN EVIDENCE BASE

The Australian Paediatric Surveillance Unit was established in 1993 to collect data on lesser-known disorders. Fetal Alcohol Syndrome was added to the list in 2001, to ascertain ‘the incidence of FAS as diagnosed by paediatricians in Australia; epidemiology, alcohol and other drug exposures during pregnancy; and use of health services (Elliott 2002). The first prevalence data estimated a rate of 0.02 per 1,000 non-Indigenous live births and 2.76 per 1000 Indigenous live births in Western Australia. The incidence of birth defects, taken from the Western Australia Birth Register, was the source of the data, and the researchers noted that including data from rural paediatric services made little difference to prevalence rates, with the exception of FAS. The results indicated an increase ‘from 0.13 per 1000 to 0.18 per 1000’ (Bower et al. 2000). In the following year, Elliott and colleagues reported on 19 children with a diagnosis of FAS and a further eight children as ‘probable’ victims, given the data were incomplete. In the years 2001–2004 inclusive, 25 cases of FAS and 49 of partial FAS were reported (Elliott, Cronin & Zurynski 2005).

A FAS interest group formed in the Northern Territory in 2002 to advance the development of a diagnostic protocol and of FAS resources. From group discussions, several recommendations emerged, proposing policymakers become 'well informed to prioritise resource allocation' and develop protocols to collect birth data to build a minimum dataset. There was a recommendation that the National Alcohol Strategy prioritise pregnant women and make FAS a priority. The absence of the alcohol industry, child and family services, corrections, disability and special education from the group was noted. There was consensus that FAS was not just an Indigenous issue, but that there was a need for 'particular strategies for particular groups' (Atkinson 2002, p. 12).

The first Australian National Workshop on Fetal Alcohol Syndrome was convened in 2001 by the Australian National Council on Drugs and the National Expert Advisory Committee on Alcohol; the event was funded by the Federal Government. The aim was articulated as a contribution 'to the future direction of policy approaches to FAS' (Stokes 2002). Professor Margaret Hamilton reported on FAS in Australia and advised of a 'growing interest in other countries with a range of approaches and detailed work; however, this workshop represents the first focus discussion on the effects of alcohol consumption on the fetus and development of the child in Australia' (Wilson 2002).

The role of the Australian Paediatric Surveillance Unit was discussed, with particular reference to how its future work might reflect the true prevalence of FAS in Australia. Several other issues were raised, not least the need to promote paediatric awareness of FASD and to address the value and belief systems of referring physicians, which influenced their action and in turn influenced their recommendations for diagnosis and appropriate referral. Questions were posed as to where physicians could refer their pregnant patients 'at risk', and where children might be referred, given the absence of trained diagnosticians. Scott Wilson, of the Aboriginal Drug and Alcohol Council in South Australia (Stokes 2002, p. 4) advised of legal awareness through training, the lack of diagnosis in major hospitals, and the discrepancy between the numbers of Australian cases diagnosed compared with overseas. Wilson also advised that most of the children in behavioural problem units in South Australia were Aboriginal, and queried if FAS was a factor.

At about the same time, Colleen O'Leary was contracted by the Australian government to undertake a FAS Literature Review. O'Leary pointed out that Aboriginal Australians were regarded 'as a high-risk group for FAS' and confirmed that 'under-ascertainment of cases may have clouded the true level of FAS in both the high-risk groups and the general community'. Further, she noted that knowledge of the risks associated with alcohol use during pregnancy and of FAS was limited, and compounded by the lack of confidence and hesitancy of the medical profession to diagnose FAS; she recommended that training should be offered in medical school and education programs (p. 2). The Review lacked reference to the known spectrum of effects, although the increased risk of maternal alcohol use in early pregnancy validated epidemiological research which at the time supported 'an association

between the excessive consumption of alcohol by women who are pregnant and the risk of FAS or FAE/ARND'. O'Leary advised that there was 'no sound evidence that low levels of alcohol consumption produce FAS and FAE/ARND' (p.1) and the National Expert Advisory Committee on Alcohol agreed: 'the amount of alcohol required to produce ARND has been difficult to establish and is surrounded in controversy' (O'Leary 2002, p. 13).

State and territory jurisdictions in Australia play a role in this history of fetal alcohol exposure and FASD prevention. In Queensland, a joint initiative of the Royal Brisbane Hospital, Women's Health Service and Mater Mothers' Hospital was announced on 9 September 2004, described as an 'opportunity for participants to consider contemporary issues associated with alcohol use in pregnancy and to identify perceived priorities for future planning'. An inability to determine the true incidence of FAS in Australia, the absence of consensus in diagnosis and lack of standardised data collection, limited research, and limited consumer awareness of the risk of alcohol use in pregnancy were listed as key challenges. Importantly, FAS was reported as presenting 'similar issues to the international scene such as being socially and economically resource-intensive within the spheres of health, education and judiciary' (Mater Hospital 2004). In respect to Aboriginal girls and women, a study of self-reported alcohol intake aimed to identify the characteristics of women accessing antenatal care in far north Queensland, and to utilise this information to plan interventions (Rimmer 2005). Of the women who participated in the study, almost 75 per cent of the 60 per cent who self-reported drinking alcohol prior to confirmation of pregnancy had stopped drinking during pregnancy. The number of women who had been unable to stop drinking or who choose to continue drinking identified a major risk factor for consideration in prevention programs as alcohol use preceding pregnancy.

The Australian Medical Association called on the Federal government to revise the National Health and Medical Research Council's proposed set of guidelines for alcohol use in pregnancy. Australian Medical Association president Bill Glasson warned there was 'compelling evidence that even small amounts of alcohol during pregnancy could harm unborn children' and claimed the guidelines were not strong enough and could mislead women (Australian Medical Association 2004). Dr Andrew Pesche (2004) was interviewed on behalf of the Royal Australian College of Gynaecologists said in response that RACOG supported the 'no amount of alcohol safe during pregnancy' position and that women in Australia were generally told not to consume any alcohol in pregnancy. He added that RACOG would not recommend a safe dose for alcohol in pregnancy: 'When adults drink alcohol it does have an effect on the brain, in varying degrees ... and that's a mature brain so you can speculate on what effect it might have on a brain that's still developing' (Pesche 2004).

In 2005 the Australian Medical Association again called on the National Health and Medical Research Council to revise its guidelines on alcohol consumption in pregnancy. The President, Dr Mukesh Haikerwal, reiterated that the Council 'should revise guidelines on alcohol consumption during

pregnancy', pointing out that the 'same call had been made the year before and there is compelling international evidence since 1989 to recommend no alcohol in pregnancy'. He added that 'Australia is lagging in its response to Fetal alcohol syndrome' (Women's Health News 2005).

Fitzgerald wrote an article in *The Australian* in which he stated that alcohol 'is not just a pressing immediate problem but a huge future problem':

Never before have young women been exposed to such high levels of alcohol consumption. In teenage years the heavy drinking of young males has been turned upside down by binge drinking in girls ... What does this mean for the future of young women – their development, careers and health and for the children they will bear? Alcohol is again relegated to be the Cinderella of public policy yet it continues to be our most harmful drug. How do you explain that? The present situation in Australia is nothing less than a scandal and politicians, the liquor industry, the advertising industry and others profit from a legal drug which has a devastating effect on our society (Fitzgerald 2004).

On International FASD Awareness Day 2005, Senator Claire Moore acknowledged the continued research conducted overseas and expressed her hope for more to be done in Australia. She described FASD to Parliament as 'a hidden epidemic' which was not adequately addressed, and argued against those 'people in our community who are peddling the line that there are safe levels of alcohol consumption' (2005).

A campaign called 'Pregnancy and Alcohol Don't Mix' was launched in South Australia in 2005, with a focus on the need to 'alert the community and in particular women of child bearing age to the risks associated with consuming alcohol during pregnancy'. At the launch Professor Eric Haan stated that FAS is estimated to be as 'common as spina bifida and Down syndrome' and 'ten times more common in disadvantaged groups'. There was a reported lack of knowledge in medical practitioners, and consumers reported a lack of knowledge and a public perception that information on the subject was vague or too complex. Professor Haan argued that

for every child diagnosed with fetal alcohol syndrome there are 3–5 who were damaged by alcohol in pregnancy, but not severely enough to be diagnosed with the syndrome. These are children with alcohol-related neurodevelopmental disorders and alcohol-related birth defects that are not often recognised as being the result of exposure to alcohol in pregnancy (2005).

In a submission to the architects of the National Alcohol Strategy (2005–2009) Miers, spokesperson for the National Organisation for Fetal Alcohol Spectrum Disorder, again wrote:

As a matter of urgency, the Strategy must include initiatives to address Fetal Alcohol Spectrum Disorder at every level – i.e. public awareness and education, surveillance, early identification and diagnosis and intervention and management. Broad-based efforts are required, given that this is possibly the most serious and far reaching health problem ever faced by Australians, we cannot afford to underestimate the devastating lifelong impact FASD has. In Australia, there is increasing evidence that alcohol use at risky levels is increasing among younger women of child bearing age. Yet, our Federal government has no policy for dealing with FASD at any level, i.e. Prevention, Diagnosis, Intervention and Management (Miers 2005).

What actually emerged in the Strategy fell short. Fetal Alcohol Syndrome was identified as a particular health concern even though, at the time, the evidence was ‘relatively small in Australia’ (National Alcohol Strategy 2006–2009, p. 23). Perhaps in light of this statement, the Ministerial Council on Drug Strategy established a Fetal Alcohol Spectrum Disorders Working Party in 2006 ‘to advise on the developments in Australia and overseas in regard to FASD and to identify best practice approaches to reduce the incidence of FASD, particularly in Indigenous communities’ (Burns et al. 2012). On a positive note, the Strategy did highlight low to moderate amounts of alcohol as causal to adverse fetal outcomes. It also marked a shift in advice to women that ‘it is morally and ethically responsible for policies to promote abstinence during pregnancy’. The recommendations proposed screening and advice for all women of childbearing age and particularly pregnant women, noting the implementation of brief interventions and referral as indicated. Newborn infants ‘heavily exposed to alcohol in utero should be referred for paediatric assessment’ (Burns et al. 2012, p. 98).

A FASD Epidemiological Conference was convened in Sydney on 5 May 2005, attracting a diverse range of professions and interest groups represented by a number of presenters including Australian researchers.¹⁴ International presenters estimated that four to five more children for each one diagnosed with FAS have neurobehavioral effects which, in the absence of structural abnormalities, can occur in otherwise normal children. Neurobehavioural abnormalities are numerous and there is no one behavioural phenotype to FAS, and fetal alcohol exposure is impossible to predict. At the conference, Heather d’Antoine spoke about the WA Aboriginal Health Survey in the late 1990s in which information had been collected from 5,300 Aboriginal children under 18 years. She said the data indicated 61% of males and 43% of females were consuming alcohol; 22.5% of Aboriginal women younger than 20 were giving birth compared to four to five per cent of the general population; the

¹⁴ Personal notes in this section were recorded at the FASD Epidemiological Conference in Sydney on 5 May 2005.

characteristic outcome of mothers seemed to reflect their own experience as affected by FASD. D'Antoine highlighted difficulties in addressing the issue: the absence of national collaboration; the need for routine perinatal data collection; and further on interventions, understanding the characteristics of Aboriginal women at risk and long-term outcomes. She considered that Aboriginal women feared disclosure, and that the fear was related to treatment and losing children to the child protection system.

Professor Carol Bower indicated most Aboriginal women abstain at a higher level than non-Aboriginal women. She presented findings that FASD is underdiagnosed or not reported; that paediatricians do not see all cases unless referred for some other reason; that there is difficulty in diagnosis and in ascertaining alcohol use; and there are ongoing concerns about labelling. Bower referenced a key research paper from 2005 on the results of a survey of health professional's knowledge, practice and opinions about fetal alcohol syndrome and about alcohol consumption in pregnancy. Citing research findings, Bower advised that FAS was 'likely under ascertained' due to a lack of knowledge of FAS by health professionals and because only 45% of health professionals routinely ask about alcohol use in pregnancy and only 25% provide information on risk consequences (Payne et al. 2005, pp. 558–564). Of the medical professionals who participated in the survey, 88 per cent had never made a diagnosis, 53 per cent were concerned about stigmatising family, and 2 per cent felt they could not deal with FAS. Suggestions from participants in the survey on how to address FAS and alcohol use in pregnancy indicated the need for resource materials (83%), information for clients (79%), a FAS diagnostic checklist (64%), a pregnancy history (43%) and training (38%).

In terms of current FASD related practices among health professions who participated in the survey, 88 per cent of medical professionals gave advice to patients; 28 per cent said they advised women to not become intoxicated; 29 per cent advised women to have fewer than seven drinks in a week; 41 per cent routinely asked about alcohol use; and 22 per cent provided information. Over one third of respondents advised they found it difficult to ask women about alcohol use.

In August 2005, Professor Elizabeth Elliott was quoted as claiming the current Australian Alcohol Guidelines were 'vague and unhelpful' and the prevalence of women's use of alcohol in pregnancy went underestimated due to lack of education offered to women by doctors and health workers. Despite the level of clinical awareness of the teratogenicity of alcohol, Dr Kenneth Clark, President of the Royal Australian College of Obstetricians and Gynaecologists, was quoted as suggesting an 'abstinence message would cause these women unnecessary anxiety. An overly simplistic approach is not always a wise one' that might lead to guilt and anxiety if alcohol was inadvertently consumed before pregnancy was confirmed (Maley 2005).

Likewise, an article in the *Sydney Morning Herald* in September 2005 reported on a claim by Dr Debra Kennedy, a paediatrician from the Royal Hospital for Women in NSW, that there was no evidence that a little amount of alcohol could cause FASD. She considered the current Australian guidelines of that time, which recommended pregnant women consume no more than seven standard drinks a week and no more than two a day, ‘were reasonable’ (Lawson 2005). Clearly, some medical professionals remained unconvinced.

7.3. RE-STATED DEMANDS FROM OUTSIDE GOVERNMENT

Educators and non-government services joined some paediatricians, researchers and NOFASD as stakeholders with an interest in FASD. The first in a series of Churchill Fellowships on FASD was awarded to Kim Crawford, Principal of Karratha Education Support Centre in Western Australia, in 2007. Crawford’s subsequent report included recommendations calling for the earliest possible intervention for children at risk of FASD, the implementation of professional learning opportunities for educators and school psychologists, an increment in current specialist support services that assist students identified through diagnosis, skilled personnel to interpret the multidisciplinary assessment findings to facilitate appropriate ‘adjustments to the students educational program to accommodate the specifics of the FASD diagnosis’, and access to supports across the lifespan (2008, p. 51).

To motivate national interest, the first National Conference on FASD was convened by the Drug Education Network in Tasmania. Attended by over 100 delegates, the event attracted two international and eight national speakers who volunteered their time to present on aspects of FASD.¹⁵ Having already published the first manual on prenatal exposure to alcohol prevention (Russell 2007) and a Guide for Parents and Caregivers (Russell 2009) I established the first prevention committee and organised international presenters to deliver training.³ The Drug Education Network conference attracted the interest of the Alcohol Related Brain Injury Service in Melbourne, and its CEO at the time arranged for Katherine Kelly (University of Washington FASD and Legal Issues); Anthony Wartnik (a former US Superior Court Judge and a member of FASD Experts) and David Boulding (retired barrister, Canada) to be guest speakers on FASD and legal issues at the launch of ‘No Blame No Shame’, a national survey on alcohol use in pregnancy produced for the Salvation Army in

¹⁵ My previous employment with the Drug Education Network (2003–2012) included project work on alcohol and pregnancy and the convening of the conference. The report I compiled is no longer available.

Melbourne. This event was to be followed by a forum on FASD and media events in Melbourne and Sydney at which many FASD stakeholders gathered to address the media. There is uncertainty as to what actually transpired in revoking the planned forum: but funding was cut; and there was much speculation at the time that the government had intervened after pressure from the alcohol beverage industry.¹⁶

At a consultation forum held in Brisbane in 2007, the Australian National Council on Drugs received representations articulating the lack of understanding and response to the extent and impact of FASD in the community. Although defunded in 2014, the Australian National Council on Drugs was described as ‘the principal advisory body to the Government on drug policy’ and as playing ‘a critical role in ensuring the voice of the community in relation to drug related policies and strategies’ (Australian National Council on Drugs 2007). The forum was advised of the Australian National Council on Drugs endeavour to promote activity on FASD for some time, and commitment to gather more information on the matter to then provide advice to governments and the community on future actions to address the issue. The Australian National Council on Drugs released a communiqué two years later in reference to a joint consultation forum with the National Indigenous Drug and Alcohol Committee. Specific issues were raised at the forum, including the importance of addressing FASD and increasing public awareness of the risks of drinking and the impact on children ‘and the need for warning labels on alcohol beverages, as is the case for some exported products’ (Australian National Council on Drugs 2009).

In April 2008, the National Organisation for FASD aimed to take their demands direct to government and sought an urgent meeting with the then Minister for Health and Ageing, the Hon. Nicola Roxon. In a letter to the Minister, Sue Miers, Lorian Hayes, Vicki Russell and Anne Russell asked for a discussion on the lack of diagnostic and support services and the absence of meaningful prevention campaigns to inform, influence and effect behavioural change in respect to alcohol use by parents in pregnancy. Excerpts from the emails received from parents about the lack of appropriate assistance from the medical profession were attached to the letter, highlighting experiences of personal humiliation and professional rudeness. There were accounts of accusations by doctors of parent overreaction or ‘jumping on the bandwagon’ and claims of a lack of medical knowledge about the complete spectrum, particularly in the absence of physical effects typical of FAS. FASD was claimed to be complicated by the absence of visible disabilities in the majority of cases, resulting in many affected children and adolescents ‘slipping through the system’ (Miers et al. 2008).

¹⁶ Author's personal recollection.

A paper titled 'The conundrum of FASD in Australia', prepared for presentation to the Minister, highlighted the issues and directions that needed to be addressed in Australia. All governments were asked to commit to 'develop social and health policy that broadens the current response to FASD beyond the medical and clinical realm to a more community based approach that acknowledges the burden of FASD on households and includes access to appropriate support services'. The Commonwealth government was urged to recognise the importance of policy direction in support of screening for FASD risk, across all clients of alcohol and other drugs, mental health, medical and gynaecological services: these services were viewed as likely points of engagement for individuals living with FASD, and for FASD-affected households. The need for specialised FASD treatment centres in each state, where people could be referred or seek FASD diagnostic and care planning including counselling, was stressed.

A further recommendation made by the group concerned government policy to address discrimination and associated disadvantages. This was argued as essential to increase access to certain critical services by individuals and families living with FASD. The group proposed the government provide funding to establish a representative peak organisation to support and advance these policy shifts, especially in the non-government alcohol and other drug, mental health, disability and justice, mental health, disability and justice sectors (Banders et al. 2008).

The meeting was secured but the Minister was unavailable on the day, and instead the group met a very recently appointed senior bureaucrat who knew little about the issue. In the post-meeting period, board members from the National Organisation for FASD wrote to the Minister's office to clarify the next stages, advising,

So there is FASD, a problem stuck between a powerful force trying to contain the process by which it enters the public arena and another power, the alcohol industry, attempting to stop it or at least slow it down from entering the public arena (Russell 2009, personal communication).

7.4. NATIONAL POLICY

On 24 April 2009 'the Ministerial Council on Drug Strategy approved an extension of the term of the current *National Alcohol Strategy 2006–2009* until 2011' (Commonwealth of Australia 2006). It is interesting to note that in terms of alcohol harms, the need for a whole of population approach was adopted. Most alcohol harms were advised as evident 'among Aboriginal and Torres Strait Islander people', and the Winemakers Federation of Australia was cited as saying that 'the misuse of alcohol is a symptom of broader problems' (p. 23). An interesting feature is the documented change in drinking

behaviours by females over 20 years in recognising an increase in the proportion who reported consuming pre-mixed spirits, 'from 14 percent to 62 percent' (p.10).

A Summary Report for a national alcohol campaign funded by the Australian government made no reference to FASD specifically, but there was a section on alcohol use in respect to pregnant women (Shanahan & Hewitt 1999, p. 10). The *National Alcohol Strategy: A Plan for Action 2001 to 2003–2004* (Commonwealth of Australia 2001) which followed proposed a 'public health approach to alcohol policy, including shaping a national effort by establishing a framework that is endorsed for community and government action' (pp. 5–6). The language is noted as cautious, with references to excessive alcohol consumption and higher risk of adverse fetal outcomes when alcohol is consumed in early pregnancy. The *Strategy* describes policy development in Canada, New Zealand and the United States as 'largely akin to Australian policy, whereby multivariate measures to reduce harm associated with alcohol use are included under the national drug strategy', and alluded to non-government initiatives as 'helping to put alcohol on the global agenda'. The International Center for Alcohol Policies¹⁷, representing the global alcohol industry, is acknowledged on page four as a source of policy resource advice. Actions are identified to develop and 'disseminate information to relevant population groups, including adolescent girls and boys and sexually active women, on the risk of excessive episodic alcohol consumption during pregnancy [and] educate clinicians involved in the care of pregnant women about high-risk drinking behaviours in pregnancy' (p. 25). The data presented in the *Strategy* indicated that in 1998 six per cent of females drank at least every day and 32.5 per cent of females drank at high risk of harm.

In 'Key Strategy Area No.2 – Protecting Those at Higher Risk', there is a reference to episodic excessive alcohol consumption as leading to congenital abnormalities and fetal death, with the greatest risk advised to be in early pregnancy. The *Strategy* acknowledges the need for education 'to target adolescent girls/boys and women of childbearing age and professionals who work with these groups'. Low-risk drinking advice is suggested as being included in this education. Ironically, the Australian alcohol guidelines from this period are regarded stronger than those to come, stating that 'responsible drinking during pregnancy must still be considered to be abstinence' (National Health and Medical Research Council, 2001).

Episodic excessive alcohol consumption during pregnancy remains an important preventable risk factor for congenital abnormalities in Australia. Studies show that episodes of high-risk drinking during pregnancy can contribute to a variety of adverse outcomes in the unborn child, including fetal

¹⁷ ICAP has since been replaced by the International Alliance for Responsible Drinking <http://www.iard.org/>

death, congenital malformation, growth retardation and behavioural deficits. The risk is greatest in early pregnancy (Commonwealth of Australia 2001, p. 10).

The formation of a FASD Working Group in 2006 at the request of the Ministerial Council on Drugs (Burns & Elliott 2009) led to the convening of a second FASD Workshop in Adelaide in 2008, called the ‘National Fetal Alcohol Spectrum Disorder (FASD) Workshop: Responding to Alcohol in Pregnancy – Where To From Here?’ It was co-sponsored by the Commonwealth Department of Health and Ageing and Drug and Alcohol Services South Australia. This second FASD workshop was perhaps one of the actions identified in the *National Alcohol Strategy* (Commonwealth of Australia 2001, p. 25) and was jointly convened by the Australian National Council on Drugs and the National Expert Advisory Committee on Alcohol. The workshop convenors had a stated aim of contributing to ‘the future direction of policy approaches to FAS’ (Stokes 2002) and an overarching goal of identifying potential future directions and strategies for responding to alcohol use in pregnancy and contributing to policy directions on FAS.

In the lead-up to this workshop, Sue Miers lobbied strongly for greater parental representation. Parents had not been included, a significant omission as the convenors intended to split participants into working groups to develop recommendations. The workshop was designed to consider issues in respect to prevention, diagnosis and management, research and training needs. Presenters covered a range of FASD issues and were key players from within the FASD research network in Australia.¹⁸ Participation had been selective; and Miers advised organisers of the definite need ‘to have input into that’ (Miers 2008). Workshop planning continued with some uncertainty as to what would happen with the information from the working groups.

Miers first wrote in September 2008 to find out more about a report (a FASD Monograph) from the FASD Workshop being prepared for the Australian Government and began correspondence with Keith Evans, Chairman of the Intergovernmental Council on Drugs FASD Working Party and Executive Director, Drug & Alcohol Services, South Australia. Miers emailed her concerns about the content of the report and expressed the opinion that the Workshop outcomes should not be referred to as a ‘community consultation’ when there was a lack of consensus by all who were present:

These problems are exacerbated by poor professional knowledge about FASD and a paucity of cross-sector support fuelled by bias and unfathomable ignorance of the skills, knowledge,

¹⁸ I attended the second workshop.

policy formulation and programme implementation that are in place in similar countries such as Canada & United States. (Miers, 2008)

The production of a FASD Monograph (Burns et al. 2012) on behalf of the Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorder included papers presented at the National Workshop and was completed to final draft in 2009 but not published until June 2012. Despite Miers' description of the Monograph as 'meaningless, flawed and inadequate as a reflection of both the scope of the problem and the difficulties experienced by the individuals, families and communities who are coping with the problem every day' (2008), over five of its recommendations were acted on prior to publication, and research on the prevalence of FASD in high-risk communities, health, justice and education professional development, the development of national screening and diagnostic criteria, service development, and research funding and the development of evidence based policy had been completed (Elliott 2013):

I am really alarmed that a monograph that is going to be used as Australia's response to FASD will be based on a 'rushed' two-day workshop that had such a narrow focus ... I think the members of the MCDS need to be made aware of these concerns (Miers 2008).

In 2008 the Federal government announced the establishment of the new National Preventative Health Taskforce, a group of experts gathered to develop strategies 'to tackle the challenges caused by tobacco, alcohol and obesity' and 'provide evidence-based advice to governments and health providers' (Department of Health & Ageing 2008). A discussion paper prepared by the National Prevention Taskforce indicated agreement for an 'effective strategy to deal with the harmful use of alcohol during pregnancy' (Scollo & Vandenberg 2008, p. 36) and acknowledged 'the impact of drinking on children, by their parents and/or other adults as a particular concern'. The authors cited the work of Dawe et al. (2007), who had estimated that '13% of Australian children aged two years or less are exposed to an adult who is a regular binge drinker', and commented on an estimated '31% of parents involved in substantiated cases of child abuse or neglect' had experienced 'significant problems with alcohol use' (Scollo & Vandenberg; 2008, p. 30).

The 2008 discussion paper pre-empted a report prepared by the Taskforce, 'Australia: the Healthiest Country by 2020' (Schultz et al. 2009), which focused attention on a wide range of health issues including alcohol and the health context for FASD prevention. For example, in Chapter 4 on alcohol, pregnant women are included as a 'specific population group', and in Key Action Area 7: Build Healthy Children and Families, the risk for fetal alcohol exposure is acknowledged (Schultz et al. 2009, p. 264). There is a reference to the estimated 47 per cent of Australian women and 10–44 per cent of Aboriginal women who consume alcohol in pregnancy, with an estimate of 10–19 per cent of the Aboriginal population of women drinkers consuming alcohol at harmful levels during pregnancy.

The authors propose that the risk for fetal harms are highest with frequent alcohol intake in the first trimester of pregnancy, but that establishing a minimal dose to risk fetal harm makes it ‘impossible to set a “safe” or “no risk” drinking level for women to avoid harm to their unborn baby’ (Schultz et al. 2009, p. 264).

A review of the Australian National Alcohol Guidelines in 2009 culminated in Guideline 4, which advised that alcohol use during pregnancy ‘can harm the developing fetus or breastfeeding baby’ and that women who are pregnant, planning a pregnancy or breastfeeding should consider abstinence as ‘the safest option’ (National Health and Medical Research Council, 2009, p. 70). Submissions had earlier claimed it was ‘impossible to set a ‘safe’ or ‘no-risk’ drinking level for pregnant or breastfeeding women to avoid harm to their unborn fetus or young baby’ and the ‘uncertainty is reflected in policy regarding alcohol use in pregnancy within Australia and overseas’ (O’Leary et al. 2007, p. 57).

7.5. FOCUS ON SOME WOMEN

By 2002 the Australian Institute of Health and Welfare had analysed data from the 2001 National Drug Strategy Household Survey, which indicated ‘59% of women reduced alcohol consumption from pre-pregnancy levels and 36% of women were abstaining’ (AIWH 2002). By default, this implied that 64 per cent of women were consuming alcohol at some level during pregnancy and 41 per cent were continuing to drink at pre-pregnancy levels. Perhaps as a consequence the 2003 Australian Alcohol Guideline, Guideline 11, should have reflected the thinking of a decade before in respect to fetal alcohol prevention; but it was less succinct. Parents now were asked to not consider drinking at all; to not become intoxicated; to have less than seven standard drinks over a week and no more than two standard drinks on any one day. Guideline 11 said that ‘risk was highest in the early stages of pregnancy’ and mentioned ‘the difficulty in identifying the exact levels of drinking which may cause harm’. The limited evidence available was interpreted to indicate that if a pregnant woman’s average consumption was less than one drink per day, ‘there will be no measurable impact on the physical and mental development of your child’, but ‘episodes of drinking above the Guideline levels considerably increase the risk to your unborn child, including the risk of miscarriage, low birth weight, cognitive defects and congenital abnormalities’ (Department of Health, Australian Government 2003).

Peadon et al. (2007, pp. 935–939) investigated the role of general medical practitioners in identifying women and children at risk of FASD, and Giglia and Binns published their findings on patterns of alcohol use by pregnant and lactating women in Perth, Western Australia in 2007 (Giglia & Binns 2007, pp. 493–500); women’s knowledge and attitudes on alcohol use in pregnancy was the subject of a national survey three years later which found a ‘disjunction between knowledge and attitudes towards alcohol use in pregnancy’ as more than 80 per cent of women surveyed ‘agreed that pregnant

women should not drink alcohol'. Increased knowledge was associated with higher levels of education but was 'not associated with attitude' (Peadon et al. 2010, p. 510). The results indicated more than raising pregnant women's awareness would be needed for prevention attempts to succeed.

In response to research aimed at elucidating 'the true association between low to moderate alcohol consumption and fetal harm' (O'Leary et al. 2007), Miers argued that this kind of research diverted attention 'from the urgent need for diagnosis and management of fetal alcohol spectrum disorder (FASD) in Australia'.¹⁹ She cited commentary from a birth mother that 'children are being sacrificed to ensure that the anxiety level of the mother is kept within acceptable limits – neither mother nor child will benefit from this. O'Leary replied that the intent of Australian policy was to carry 'less emphasis on abstinence and more on avoiding intoxication and ensuring low-level alcohol consumption', and that de-prioritising the impact of low to moderate alcohol exposure would be 'short-sighted' given almost 80% of women reported drinking in the three months prior to pregnancy and 14% reported binge drinking. Alarming, '47% report that their pregnancy was unplanned', so health professionals needed 'a true estimate of risk to the fetus and know what additional factors (e.g. genetics and nutrition) may alter risk, and women deserve to be well informed' (O'Leary et al. 2007).

In a letter to the editor of the *Medical Journal of Australia*, Morley et al. (2007) sought to 'stimulate discussion' on the subject, proposing that this should address maternal alcohol intake 'across the range from minimal to heavy drinking, as well as information on drinking patterns and alcohol intake at different periods of gestation; the influence of maternal size, body composition and level of nutrition during pregnancy and ... the use of alcohol with food intake' and 'possibly maternal genotype'. They concluded with the comment that 'good studies' might explain the 'variable link between maternal alcohol consumption and adverse sequelae in the offspring' (pp. 315–316).

Data collected between 1995 and 1997, when non-Indigenous women were asked questions about any alcohol use prior to pregnancy and then again at each trimester, revealed most had consumed alcohol in the three months prior to pregnancy, and almost 60 per cent had consumed alcohol in the first trimester. While the number of occasions of drinking declined over gestation, almost 15 per cent of women consumed alcohol beyond the guidelines, although this decreased to 10 per cent in the second and third trimesters. An estimated 47% of women 'did not plan their pregnancy', which suggested that many unborn children were inadvertently exposed to alcohol before the pregnancies were confirmed.

¹⁹ NOFASD Australia internal correspondence.

Some ‘16% of Australian women do not know that the effects on the unborn child of drinking while pregnancy are permanent’ (Colvin et al. 2007). There was acknowledgement that better evidence is required on the complete spectrum of alcohol-related birth defects to better inform interventions (pp. 276-284). Rates of FASD were considered to be underascertained in Australia due to lack of clinical knowledge about FASD and appropriate interventions and the fear of stigmatising family and child (Payne et al. 2005, pp. 558–564).

A study in Western Australia examined the pregnancy characteristics of women who gave birth to children with fetal alcohol syndrome, to identify women at risk and better target interventions. The researchers found the mothers were older, had given birth to more children, ‘smoked more cigarettes, attended fewer antenatal visits and experienced more antenatal and delivery complications than mothers of controls’ (Coyne et al. 2008, p. 240–247). Findings by the paediatric outreach service on the health of Aboriginal and Torres Strait Islander children were also published that year, ‘with a prevalence rate for fetal alcohol spectrum disorder ... at least 15/1000 (1.5%)’ (Rothstein et al. 2007, pp. 519–521). O’Callaghan and colleagues also published a paper on the impact of moderate levels of alcohol during pregnancy on a group of children 14 years later, determining that less than one glass a day held no association with attention, learning or cognitive outcomes: ‘the strongest estimates among those consuming more than 1 glass/day’ during in late pregnancy were ‘associated with increased prevalence of overall learning difficulty’ (O’Callaghan et al. 2007, p. 115).

By 2005 Elizabeth Russell had published the first of three books on FASD. *Alcohol and Pregnancy: A Mother’s Responsible Disturbance* told of her first-hand experience of being a birth mother of and raising children diagnosed with FASD. The book opened a conversation, perhaps for the first time in Australia, of the experiences of non-Aboriginal women who use alcohol. The second book published in 2007, *Alcohol and Pregnancy: No Blame, No Shame*, is a compilation of chapters written by different authors; and *Strategies for Employment Services Specialists* (2008) concerned the difficulties faced by adults affected by FASD on entry to the workforce, and the creation of supportive workplace environments. These publications are noted as ‘the first books on FASD in Australia’ (Russell Family Fetal Alcohol and Disorders Association 2013).

Bec Yeats (2008, p. 4) identified in a Gender Impact Statement how ‘the intense social stigma of drug use prevents women accessing health services’ and how ‘this is compounded for women who are pregnant’. Alcohol was not mentioned as a general theme, but in respect to Indigenous women’s drug use during pregnancy, it was said to be ‘characterized by higher levels of alcohol and cannabis use than non-Indigenous women’ (p. 5). From 1996 to 2003, researchers surveyed 6,000 women to determine overall patterns of alcohol use. The results revealed 87 per cent of the women had consumed alcohol at some time in their life, 82 per cent in the past 12 months. Thirty-four per cent were identified as risky drinkers, four per cent as harmful drinkers and one per cent as alcohol

dependent. Eight per cent were classified as currently having a pattern of harmful alcohol consumption; 'these women were more likely to be younger (17–44 years), single, or living in a de facto relationship' (Fleming 1996, pp. 1325–1334). Study of longitudinal changes in alcohol consumption between 1996 and 2003 found 'the majority of women had not changed their level of alcohol consumption over 5–7 years between surveys' (Young & Powers 2005, p. iv).

In Western Australia, the *No Alcohol is the Safest Choice* campaign, based on research carried out at Edith Cowan University, 'found that many women are often confused about whether small amounts of alcohol during pregnancy are safe' (Edith Cowan University News 2012). Among other post-evaluation findings, 'a high number of women correctly recalled the key messages of the campaign' and 'approximately three out of four women who had seen the campaign felt that it made them consider the health effects of drinking alcohol while pregnant, and that it made them concerned about the effect that alcohol can have on an unborn child' (Drug and Alcohol Office, WA).

A paper titled 'Reducing Alcohol Use During Pregnancy: Listening to Women Who Drink as an Intervention Starting Point' was based on a self-completion survey of 142 pregnant women in Western Australia. The results found women who 'continued to drink were more likely to have drunk in previous pregnancies and during the preconception period' and 'were most likely to drink in their own home or at the home of a friend'. The researchers concluded that participatory research 'with women who drink while pregnant can assist in identifying potential intervention strategies that have resonance with this group and therefore more potential for creating behaviour change' (McBride et al. 2012, pp. 6–18).

The issue of rights for the unborn child versus the rights of the mother emerged in late 2010. While the Alcohol Education and Research Foundation (now known as the Foundation for Alcohol Research and Education, or FARE) reported on the outcomes of a survey of over 1,000 participants on community attitudes towards alcohol and found one in three women admitted drinking during pregnancy or while breastfeeding (Foundation for Alcohol Research and Education, 2010).

In the same year, the Australian Medical Association (2010) released a position statement on fetal welfare and the law in which a spokesperson claimed concern 'that some foetuses will suffer permanent harm in utero because of the mother's behaviour [and] the mother's exercise of her rights to refuse or ignore medical advice'. Alcohol consumed during pregnancy crosses the placenta and can cause complications of pregnancy and damage to the developing foetus, including foetal alcohol syndrome. The risks are greatest with high, frequent alcohol consumption during the first trimester of pregnancy (Australian Medical Association, 2010). Damien Brown (2010) weighed in with an article based on a Tasmanian Greens paper and suggested 'giving legal rights to the fetus and prosecuting mothers caught using drugs or alcohol'. This coincided with an online newsletter published by the

Centre for Independent Studies which examined this same conflict. Hudson (2010) approached this issue by identifying maternal drinking as a 'harder case when behaviour doesn't break the law'. FASD was described as 'transgenerational' and the writer noted that it was 'not illegal for pubs and clubs to refuse to serve pregnant women'.

In their investigation into the prevalence and predictors of Australian women's alcohol use in pregnancy, Maloney et al. found '29 percent of women who were pregnant in the past 12 months' had used alcohol, and most (95%) had 'reported a reduction in the quantity of their alcohol use while pregnant or breastfeeding'. Older age, higher educational attainment, and increased time engaged in breastfeeding 'were significantly associated with alcohol use': 'These results indicate that public health education campaigns about the risks of alcohol during these periods are needed' (Maloney et al. 2011, p. 9).

This was followed by an investigation in New South Wales on the relative influence of geographical location and maternal characteristics on alcohol use in pregnancy, which found 'no geographic differences'. Women in regional and remote areas, however, were less likely to attend specialist obstetric hospitals (Burns et al. 2011, pp. 1230–1237). Predicting attitudes and behaviours influencing women's intention to consume alcohol in pregnancy and the challenges this posed for health professionals (Peadon et al. 2011, p. 584), along with the results of an evaluation of the supportive impact of educational materials to support prevention in this context, were published (Payne et al. 2011, pp. 316–327).

Published research from Western Australia raised consternation among those committed to raising awareness of the risk of fetal alcohol exposure. Robinson et al. (2010) published research on low to moderate prenatal alcohol exposure and the risk to child behavioural development, drawing on data collected from 2,900 pregnant women (between 1989 and 1991), and a follow-up review of these children at 14 years of age (2003–2006). Australians working in the FASD arena and international experts on FASD were concerned by the research statements, and particularly of their interpretation by media. For example, Gideon Koren (Director of the Motherisk Program, The Hospital for Sick Children, Toronto, Canada) took issue with the study's sample group of mothers and called the study irresponsible, arguing that describing moderate alcohol consumption as 'harmless' did little other than ameliorate parent anxiety.²⁰

²⁰ V Russell, personal recollection.

As spokesperson for NOFASD, Miers wrote to the Telethon Institute for Child Health Research, which had sponsored the Robinson research (known as the Raine Study), and expressed her concern about the message this was giving women (Miers 2010). The paper, she wrote ‘has just put us another ten steps backwards in our fight for the support that individuals with FASD deserve [and] sends out mixed messages’. Somewhat ironically, Robinson et al. (2010) are cited in a media article as advising women to ‘ask their obstetric care provider (obstetrician, midwife, family doctor, etc) and work with that person on their decision regarding alcohol’ (Brooks 2010).

7.6. FOCUS ON ABORIGINAL COMMUNITIES

As if to validate an earlier claim of a higher risk of FAS in Aboriginal communities, Harris and Bucens (2003) published a prevalence study based in the Northern Territory. This found extremely high prevalence of FAS in Indigenous populations, among the highest in the world.

Recent estimates of the prevalence of FAS are 2.76 per 1,000 births among Aboriginal and Torres Strait Islander children, compared to 0.02 per 1,000 births among children in the general population (Bower et al. 2000). The prevalence of FAS in the Northern Territory was 0.68 per 1,000 live births in the general population and between 1.87 and 4.7 per 1,000 live births for Aboriginal and Torres Strait Islander peoples between 1990 and 2000 (Harris & Bucens 2003).

Harris and Bucens’ (2003) research was challenged, with criticisms of missed cases and a lack of recorded information (Handcock 2004).

A prospective national prevalence study on FAS in Australia was published four years later by the Australian Paediatric Surveillance Unit from data collected from more than 1,150 paediatricians each month; 169 reported cases were noted. Of this number, 92 met the criteria for FAS with most children exposed to a high risk of alcohol *in utero* (Elliott et al. 2007). The data revealed 65% of those diagnosed with FASD were Aboriginal, approximately 50% had a sibling with FAS, and about 40% lived with a biological parent (Elliott 2008).

Beginning in 2007, a collaboration of the Nindilingarri Cultural Health Services, Marninwarntikura Woman’s Resource Centre, the George Institute for Global Health and the Discipline of Paediatrics and Child Health, University of Sydney Medical School, attracted Commonwealth research funding of \$1.5 million to conduct Australia’s ‘first ever prevalence study of FASD’ with experts in local Aboriginal culture, Indigenous health, paediatrics, research, epidemiology and human rights. The

Lililwan Project is part of a broader community strategy called Marulu: Overcoming FASD and Early Life Trauma in the Fitzroy Valley (George Institute for Global Health 2012).²¹

A speech on FASD and its impact in the Kimberley region was made by Senator Judith Adams (Adams 2009) and included reference to an expected FAS incidence rate of 8.5: 1000 or ‘100 times the incidence in non-Indigenous populations’. The Final Report from the Senate Committee on Regional and Remote Indigenous Communities (2009), of which Senator Adams was a member, expressed a keenness to ‘inquire further into the prevalence of Fetal Alcohol Spectrum Disorder’ and recommended governments across Australia give greater recognition to the issue of FASD in the formulation of health, education and justice policy:

Recommendations in previous reports include increasing access to alcohol and other drug rehabilitation and detoxification services and the development of a communication strategy for parents caring for a child with FASD. The committee considers that a further inquiry into FASD in regional and remote Indigenous communities is required. (Senate Committee on Regional and Remote Indigenous Communities 2009, p. 16)

High-risk drinking in pregnancy and few diagnostic services for FASD led Aboriginal leaders in the remote Fitzroy Valley in Western Australia to prioritise FASD as a community concern. The community in the Kimberley region in Western Australia applied enough pressure on the alcohol industry to draw a response from the Australian Hotels Association in their region. The Australian Hotels Association announced ‘a voluntary ban among pregnant women in the Kimberley’ with the aim of reducing the prevalence of fetal alcohol syndrome; this ban would be in place from 1 April 2009. The Australian Hotels Association claimed that ‘90 percent of women in Halls Creek are alcoholics and 30 percent of the children born in the community have foetal alcohol syndrome’ (ABC News 2009).

The Lililwan Project was launched in 2010, a partnership of Aboriginal organisations and leading research organisations, to determine ‘the prevalence of FASD and other health and developmental problems in school-aged children residing in the Fitzroy Valley, providing data to inform FASD prevention and management’. A population-based study of children born in 2002 and 2003 and residing in the Fitzroy Valley, and diagnostic interviews with parents/carers ‘to determine the demographics, antenatal exposures, birth outcomes, education and psychosocial status of each child’

²¹ The George Institute for Global Health website lists media interviews and fourteen presentations made on this work. Source: <http://www.georgeinstitute.org/search/node/Marulu>

were followed up by the application of ‘interdisciplinary health and neurodevelopmental assessment’ (Fitzpatrick et al. 2012).

In 2010, the Western Australia Government sponsored a FASD Prevention Aboriginal Consultation project titled ‘Strong Spirit Strong Future – Promoting Health Women and Pregnancies’. The overarching aims of the project were described as culturally sensitive resource development, improving community awareness through a media campaign, and offering education and training for health professionals and other workers. A forum ‘to seek the input and guidance of senior Aboriginal professionals, Aboriginal community members, and people who provide services to Aboriginal people, into the project’s development’ was attended by 65 participants. The forum provided an introduction to the project and informed participants

of current evidence based responses to FASD prevention; consult with Aboriginal professionals and community members so they can contribute, share ideas in the development of culturally secure resources and prevention responses for the community and build community and sector networks to support the sharing of knowledge, project awareness and implementation and seek input into the consultation framework. (Government of Western Australia 2010)

The Australian Senate Committee: Regional and Remote Indigenous Communities concurred that the prevalence of FASD in regional and remote Indigenous (and other) communities was too high, and made recommendations about ‘raising awareness of the condition and developing strategies to look after afflicted individuals’. Ms Sonia Schuh, from the Napranum community, informed the Committee in a subsequent interview that approximately ‘80 per cent of our children are showing symptoms of Fetal alcohol syndrome in many different areas – lack of concentration and all of that kind of stuff’, and that training was being sought ‘because none of us are trained in Fetal alcohol syndrome’ (Australian Government Hansard 2010).

By 17 July 2010, the Australian government had announced the first Australian study (\$1 million) into the prevalence of FASD in the Fitzroy Valley in Western Australia (Banks 2010):

The population prevalence of FAS/pFAS in remote Aboriginal communities of the Fitzroy Valley is the highest reported in Australia and similar to that reported in high-risk populations internationally. Results are likely to be generalisable to other age groups in the Fitzroy Valley and other remote Australian communities with high-risk alcohol use during pregnancy. Prevention of FAS/pFAS is an urgent public health challenge.

Aboriginal researcher and FASD educator Lorian Hayes offered something new in a 'life cycle framework' she applied to understand, with cultural sensitivity, the complex relationship between historical, political and cultural factors which contribute to Aboriginal women's high-risk use of alcohol. Hayes suggested that the individual is 'inextricably tied to the culture in which he or she exists' and 'like pregnancy, alcohol is a normal part of the life cycle within a toxic social environment' (2012, p. 21).

7.7. COMMONWEALTH INQUIRY – A TURNING POINT?

On 8 November 2011, the then Minister for Families, Housing, Community Services and Indigenous Affairs in the previous Labor Government, the Hon. Jenny Macklin MP, and Minister for Health and Ageing, the Hon. Nicola Roxon MP, asked for an appointed Committee to inquire into and report on the incidence and prevention of fetal alcohol spectrum disorders. The Committee tabled its report on 29 November 2012. In their respective speeches to the House of Representatives, Graham Perrett MP and Dr Sharman Stone MP submitted that it was 'a hidden epidemic happening right now across Australia [and] one of the most important inquiries we can run in our federal parliament' (Hansard, House of Representatives 12/2/2012).

Over ninety submissions were received and more than 120 interviews were conducted. Of these, fourteen individuals were not associated with any organisation; most were foster carers. Six people represented the beverage alcohol industry and nineteen represented the Kimberley Region of Western Australia, some of them directly involved in the Lilliwun Project. Professor Elizabeth Elliott represented three organisations: The University of Sydney, The Royal College of Physicians and the Children's Hospital at Westmead, NSW. One submission came from the National Indigenous Drug and Alcohol Committee (NIDAC) in the form of a position paper, 'Addressing Fetal Alcohol Spectrum Disorder in Australia' (Stokes 2012). In their submission, FASD is acknowledged as a serious issue but neither uniquely Indigenous nor specific to pregnant women: 'NIDAC considers FASD to be an issue facing the country as a whole and one that needs to be addressed by the whole community' (p. 2).

In the Committee's report called 'FASD: The Hidden Harm' (House of Representatives Standing Committee on Social Policy and Legal Affairs 2012), 19 recommendations were made (for a complete list of recommendations, see Appendix 3). In brief, the Committee called on the Australian Government to release a FASD National Plan of Action by 1 June 2013 and to form a FASD Reference Group to report, oversee and advise relevant Commonwealth Government ministers on Plan. There was a call for a report within 12 months on the progress of the implementation of a national FASD diagnostic and management services strategy, and within five years on progress towards eliminating FASD in Australia. Underascertainment of FASD in Australia was explained as a

consequence of a number of factors including the absence of ‘full agreement on the definition and scope of FASD, complexity of diagnostic tests, variability in health professionals’ understanding of and ability to diagnose FASD, and a reluctance to diagnose due to social stigma associated with this condition’ (O’Leary 2004). In a media release, the chair of the Standing Committee on Social Policy and Legal Affairs advised that despite this limitation, some remain convinced ‘that this is an important public health matter that should be managed consistently across all state and territories’ (Perrett, 2012).

Further, all health professionals are to be made fully aware of the National Health and Medical Research Council Alcohol Guidelines that advise women not to drink while pregnant. How alcohol consumption impacts on pregnancy and the developing fetus is to be incorporated into all general practice and midwifery training together with training in how to raise and promote discussion on the Alcohol Guidelines and alcohol consumption with women and skills development in asking women about alcohol consumption and recognising and responding to women at risk (pp. 67–68). Further, all health professionals are recommended to be promoting the consistent message that not drinking while pregnant is the safest option, in line with the National Health and Medical Research Council Guidelines. Mechanisms for data collection on women’s alcohol consumption during pregnancy and a national public awareness campaign and specific campaigns targeting youth and Indigenous peoples are recommended to be in place no later than July 1 2013 (p. 69). The health advisory label is recommended to be included on the packaging of all pregnancy and ovulation testing kits by 1 October 2013 and ‘health warning labels on alcoholic beverages’ by January 2014 (p. 70).

Informed by experts, including representatives from the alcohol industry, the Standing Committee on Social Policy and Legal Affairs reported ‘that current regulation and voluntary programs regarding alcohol labelling are not functioning effectively and are unlikely to ever do so given the commercial realities of the alcohol industry’. Strategies to assist Indigenous communities in managing issues of alcohol consumption and to assist community-led initiatives to reduce high-risk consumption patterns and the impact of alcohol were recommended, as were ‘effective strategies for pregnant women with alcohol dependence or misuse’. There was a call for ‘an independent study into the impacts of the pricing and availability of alcohol and the influence of these factors in the changing patterns of alcohol consumption across age groups and gender’ and a second ‘independent study into the impacts and appropriateness of current alcohol marketing strategies directed to young people’ which ‘should be completed by 1 October 2013’. These independent studies were to be followed by ‘a National Alcohol Sales Reform Plan aimed at reducing the harms caused by irresponsible alcohol consumption across Australia’ (House of Representatives Standing Committee on Social Policy and Legal Affairs 2012, p. 86).

The rollout of the Fetal Alcohol Spectrum Disorder diagnostic instrument and ‘the development of a training and user manual ... should be available for use by 1 October 2013’ (House of Representatives Standing Committee on Social Policy and Legal Affairs 2012, p. 111), and ‘followed by a mechanism to collect and monitor diagnostic data in order to assess the effectiveness of prevention strategies and patterns of FASD occurrence’ and a ‘diagnostic and management services strategy’ to be monitored and informed by the FASD Reference Group with attention to ‘awareness amongst all general practitioners and child and maternal health professionals of the causation and clinical features of FASD and the importance of early diagnosis and intervention’. There was a call for diagnostic services to be made available in regional and urban areas together with post-diagnostic management methods based on international best practice (p. 106).

It is a little bit of an empty diagnosis if you make a diagnosis of foetal alcohol syndrome [sic] disorder but you do not have any services to apply to those children. If there were increased recognition from which some funding for remedial therapy flowed, then I think that would drive the recognition of the condition and certainly help improve diagnosis and status of the condition (House of Representatives Standing Committee on Social Policy and Legal Affairs 2012, p. 106).

Educational materials aimed at raising awareness about FASD were to be ‘developed and monitored and informed by the FASD Reference Group’, particularly for special education teacher aides and class teachers, parents, foster carers and foster care agencies, police and court officials, youth workers and drug and alcohol officers, and officers in correctional facilities and juvenile detention centres (p. 146). FASD was recommended for inclusion in the List of Recognised Disabilities and the Better Start for Children with a Disability Initiative (p. 146). Finally, the Committee called on the Commonwealth Government to recognise that people with FASD have, among other disabilities, a cognitive impairment, and to amend the eligibility criteria to enable access to support services and diversionary laws (p. 147).

The Committee is grateful for the unstinting work of individuals and organisations that have contributed to increasing awareness and knowledge of FASD and its prevalence in Australia and have lobbied for action, often without recognition or remuneration. These efforts have been the catalyst for this parliamentary inquiry and the actions that will follow (Perett in Standing Committee on Social Policy and Legal Affairs 2012, p. 106).

The Australian National Preventative Health Agency made a submission to the Inquiry into FASD (Australian National Preventative Health Agency, 2009) in which prevalence was identified as difficult to ascertain; proposed that greater accuracy would follow the implementation of ‘routine assessment and recording of maternal alcohol use during pregnancy, education about diagnosis of

FASD, and methods for collecting national data’ (p. 3). In respect to future prevention initiatives, the National Preventative Health Agency proposed that strategies must both be comprehensive and be specifically addressed to those already identified as high-risk groups, such as the socially and economically disadvantaged and Indigenous communities ‘where differences in the incidence of FASD have been reported’ (p. 6). The report continued to identify specific strategies needed to address the rates of FASD, estimated at ‘three and seven times higher in the Indigenous population’; the source of this information was its own (Australian National Preventative Health Taskforce 2009).

Anticipating the release of ‘FASD: The Hidden Harm’ report, the Foundation for Alcohol Research and Education released their National Action Plan on FASD, a product of consultation with thirty-three FASD researchers, clinicians and parent and carer groups. The Plan was launched at Parliament House, Canberra in September 2012. In this document, Fetal Alcohol Spectrum Disorders are cited as ‘the leading preventable cause of non-genetic, developmental disability in Australia [but despite this] over the last three decades FASD has been largely overlooked, with little or no support in its prevention, diagnosis, early intervention or management’. With an estimated cost of \$37 million allocated for the first three years, the Plan has five priority areas: to raise community awareness, improve diagnostic capacity, help individuals living with FASD to ‘achieve their full potential’, improve data collection, and address ‘the higher prevalence of FASD among Aboriginal and Torres Strait Islander peoples’ (Foundation for Alcohol Research and Education, 2012).

At a meeting sponsored by the Commonwealth government in 2012,²² those people involved in current government-funded FASD projects presented updates. Of the nine presentations, four concerned activities in Aboriginal communities: the prevalence study in the Fitzroy Valley, Western Australia, the development of Indigenous communication resources, a mothers and babies project in Ord River Valley, Western Australia, and a community development project in Tennant Creek. A collaboration of The University of Sydney Medical School, the George Institute for Global Health and Nindilingarri Cultural Health Services, and Marninwarntikura Women’s Resource Centre, funded by the Australian Government (\$1.5million), undertook the project in the Fitzroy Valley, Western Australia to determine prevalence. There was separate discussion about an update to the FASD monograph titled *Fetal Alcohol Spectrum Disorder in Australia*, first drafted in 2008 following the second National FASD Workshop held in Adelaide.

In recognition of the ‘proven gaps’ in diagnostic knowledge and practice, the Telethon Institute for Child Health Research called for the development of national diagnostic capacity based on the 4-digit

²² I attended as one of the speakers representing NOFASD Australia.

diagnostic code through the University of Washington (Mutch et al. 2009, pp. 79–81). An Australian FASD collaboration was formed after a recommendation by the intergovernmental committee ‘Drugs Working Party on Fetal Alcohol Spectrum Disorder’, led by Professors Elizabeth Elliott and Carol Bower, to identify and evaluate international ‘existing screening and diagnostic instruments and clinical practice guidelines’ and consult widely to gather opinion in Australia (Jones 2010).

To inform the project, a modified Delphi study was undertaken ‘to identify health professionals’ perceptions about screening for FASD in Australia’. The project involved 95 participants surveyed for their opinions. A second survey reconnected with 81 of this number for follow-up. Although highest agreement was reached on targeted screening of ‘siblings of known cases of FASD (96%) and children of mothers attending alcohol treatment services (93%)’, consensus agreement was also reached on targeted screening ‘at birth (76%) and in childhood (84%)’. There was no consensus on ‘the need for universal screening at birth or childhood’ (Watkins et al. 2013, p. 13).

Dr Doug Shelton in 2013 was the fourth Australian to be awarded a Winston Churchill Fellowship specific to FASD. His research focused on building a comprehensive assessment and intervention service for children with FASD (Shelton 2014). Kim Crawford’s 2007 (p. 114) scholarship had focused on FASD in education, while Prudence Walker (2008) examined case planning and best practice within the context of cultural connection and the sense of identity and belonging within families of origin. Western Australian Magistrate Catherine Crawford (2014) travelled to North America and New Zealand to learn more about how FASD-affected young people in the criminal justice system are dealt with in other jurisdictions. Overall, education, diagnosis, social services and justice issues for those living with FASD were reported on through experiential based learning and discovery.

The Commonwealth National FASD Action Plan to reduce the Impact of Fetal Alcohol Spectrum Disorders 2013–14 to 2016–17 was perhaps in response to the plan developed by Foundation for Alcohol Research and Education previously mentioned and more certainly, to the first of nineteen recommendations made in the report into the prevention, diagnosis and management of FASD (House of Representatives Standing Committee on Social Policy and Legal Affairs 2012). The Australian Government committed almost \$9.5 million to carry out the key actions contained in this four-page document. The first priority concerned targeting the whole community with consistent messages about risk, using the National Health and Medical Research Council Alcohol Guidelines (2009). The second priority focused attention on secondary prevention, targeting women with alcohol dependency; the third on diagnosis and management; and the fourth on ‘targeted measures supporting prevention and management of FASD within Indigenous communities and families in areas of social disadvantage’. The fifth key action focused on national co-ordination, research and workforce support, and the formation of a national technical committee of experts to ‘ensure programs intended to support

children with disabilities and families with multiple disadvantages are aware of this impact and appropriately responsive’ (House of Representatives Standing Committee on Social Policy and Legal Affairs 2014, p. 4).

The Commonwealth National FASD Action Plan was drafted from the preceding government’s tabled FASD Action Plan while that government was in caretaker mode pending an election. Unlike the previous government’s draft plan, there was no broad consultation and the policy document was released with 24 hours’ prior notice.²³ Significantly, the funding allocation was reduced from the previous government’s estimate of \$20 million allocation to \$9.4 million, and any previous policy references to support services for individuals and their families were removed. Priorities were identified as the establishment of a National FASD Technical Network to guide government policy, targeted spending in Aboriginal or communities of disadvantage, secondary targeted prevention for women at high risk of alcohol use in pregnancy, workforce training, and research including the completion of the Australian FASD Diagnostic Instrument. A little more than 16 per cent of funding was allocated to prevention; almost 34 per cent to 13 treatment services to prioritise support pregnant women; approximately 5.4 per cent to diagnosis and management; almost 44 per cent to Indigenous resources development to be implemented nationally, and just over one per cent to support the National FASD Technical Network.²⁴

7.8. SUMMARY

FASD policy falls within the governance of the *National Drug Strategy 2010–15*, in which a harm minimisation approach aims at building safe and healthy communities ‘by minimising alcohol, tobacco and other drug-related health, social and economic harms among individuals, families and communities’ (Ministerial Council on Drug Strategy, Commonwealth of Australia 2011, p. ii). The alcohol policy approach since 1985 has been based on a partnership between health and law enforcement and the involvement of all sectors of government, the non-government sector, and the community. The approach is structured on three pillars: ‘demand reduction, supply reduction and harm reduction’, and overall management is the responsibility of the Intergovernmental Committee on Drugs (National Alliance for Action on Alcohol 2014, p. 8). FASD is now documented within the harm reduction pillar, which aims to ‘reduce the adverse health, social and economic consequences of the use of alcohol, tobacco and other drugs’ (Ministerial Council on Drug Strategy, Commonwealth of

²³ NOFASD Australia correspondence.

²⁴ Personal notes.

Australia 2011, p. ii) and linked as a particular issue in ‘some Indigenous communities’ (p. 17). The Strategy proposes that

coordinated education and information campaigns and other clinical and community-led strategies are needed to help prevent FASD, and action is needed to improve the diagnosis and clinical management of affected children and to make available appropriate supports to those children and their families. (Ministerial Council on Drug Strategy, Commonwealth of Australia 2011 18)

Although the implication of alcohol use in pregnancy was medically known in Australia in the 1980s it seems little action was taken to raise public awareness. Public knowledge of risk of alcohol in pregnancy and the fetal alcohol spectrum did not become evident until Sue Miers persisted in sharing her personal learning with people who would listen, in the first decade of the new millennium. The implementation of policy recommendations made by NOFASD Australia advocates in 1999 have been resisted by government and the story of FASD in Australia is one of containment. The issue gained substantive policy interest only when the Australian Paediatric Surveillance Unit took up the issue in 2001, and from this point research and the pursuit of an Australian evidence base evolved. Mobilised as a health issue, the story of FASD was reframed as a medical condition, using rhetoric that associated the condition with high-risk patterns of alcohol consumption in pregnancy and supported by available prevalence data. FASD is also mobilised in policy as an Aboriginal problem, or of those girls and women with an alcohol problem. This contained bias is supported by the alcohol industry, an industry that government is reluctant to regulate.

All three strands (medical condition, higher prevalence linked with Aboriginal communities and the connection with high-risk patterns of drinking) endorse the message that responsible drinkers should not be concerned. This is also reflected in the progress events recorded in the United States and Canada. This research now turns to the data collected from thirty-two interviews conducted with parents and carers and those working in a range of roles within the FASD arena, to discover if these same issues concerning FASD are reflected in participants’ personal and professional responses.

CHAPTER 8 STORIES FROM THE FASD FIELD

In this chapter, data collected from the interviews with stakeholders in the United States, Canada and Australia is organised according to key themes: original demands for problem attention; advocacy and collaboration; the love of alcohol; girls, women, mothers and stigma; First Nation and Aboriginal peoples; the medical profession and diagnosis; estimating prevalence and funding; and beyond 2013. The themes are not discrete categories as the opinions and thoughts of participants often interconnect. What emerges is stakeholders' diverse frames of reference, even within the same profession or role, and across all inquiry areas. Despite which question was posed to participants, responses revealed FASD as a problem, with limited agreement on who should have the authority to define that problem and influence decisions made about it.

8.1. ORIGINAL DEMANDS FOR PROBLEM ATTENTION

There were varied opinions on the original source of influence on approaching the problem of FASD in the United States. For one, influence did not come from a 'population groundswell' (HP0106) but from scientific evidence from the University of Washington on the connection between maternal alcohol use and adverse fetal outcomes. For others, the source of greatest influence was a small group of interested federal public servants, federal politicians or advocacy groups (HP0106, RS0105; MD0107), and 'social scientists, tribal and community leaders' willing to champion increased awareness of the risks of alcohol use in pregnancy and the need for prevention programs (BS0101). Another participant expressed the view that FASD prevention has not been 'well done' (RS0108). A positive influence in the United States were strong advocates within the FASD field who understood 'the gaps', not just scientists but as people with 'a deep commitment to interact with people in all situations on all facets of the issue' (NG0111).

In Canada, information on fetal alcohol and FAS was reported to have been made publicly available by the parents of children recognised as at risk of fetal alcohol exposure. Parents were also aware of the work on fetal alcohol exposure at the University of Washington because of its close geographical proximity to Western Canada (GP0215), and the relative ease of accessing FAS training (AP0216). Parents were the original grassroots group, who generated wider attention and were then supported by other parents employed 'at very senior levels', already in positions inside government. Some remained 'nameless', possibly because their own children did not just 'drop out of the sky' (AP0213). Past prime minister 'Chretien "got it" as the foster parent of a child with FAS and did a lot for Aboriginal people' (RS0217). Dr Sterling Clarren, who had tenure at the University of Washington and also practised in British Columbia, influenced many local service providers in terms of the training he provided (GP0215).

A counterargument was that middle level bureaucrats were more influential (RS0217), or ‘frontline service providers and community advocates’ but not families (SP0222). Two Canadians thought it was the broader representation of people – politicians, civil servants and community members – who brought the problem to the attention of policymakers and the public (AP0216). For others, Dr Clarren’s research was regarded as ‘compelling’ and ‘his reasonable, thoughtful, scientifically based information’ was valuable in attracting ‘considerable national and international attention’ (ET0212). Another participant spoke extensively about the work of Dr Kwadwo Ohene Asante in British Columbia: his influence on the establishment of a diagnostic clinic in 2000, and his multi-disciplinary approach to diagnosis and support (AP0216). Other figures were also mentioned:

One leader that comes to mind is Audrey McFarlane, Executive Director of the Lakeland Centre for FASD and co-chair of the Canada Northwest Research FASD Network. In the past, Mary Berube and Donna Debolt were instrumental in the development of the first Alberta FAS Partnership. The Ministry of Children and Youth services continues to be the driving force for FASD prevention and supports as the banker for the FASD-CMC, which is the group responsible for implementation of the 10-Year Strategic Plan (GP0215).

FASD in Canada ‘has no federal support ... and it has much provincial support’ (LP0219). At this level, a FASD committee formed in Alberta in 1994, with the aim of raising awareness to build understanding by targeting as many women as possible (SP0222). One participant claimed a number of communities in Alberta were influential in ‘driving local prevention and support initiatives’ and were supported by a ‘political appetite to address the issue’. The government in Alberta (and other parts of Canada) recognised the high cost and loss of potential that FASD causes, and for the most part the long-term savings of effective FASD prevention were recognised as an acceptable return on investment in social and health programs (GP2015).

The late Carol Legge, who wrote the first report on FAS, developed the first provincial strategic plan, and set up the BC Consultation group, was described as pivotal in her role as a provincial public servant (AP0216). For another Canadian, government awareness was evident in the development of a FAS Community Action Guide and the FASD Strategic Plan. In the planning stage, principles were set down and the intent of the Plan was determined with a focus on identifying points of collaboration (RS0217). Poole (2013) described the process as first ‘identifying points of collaboration’ across the fields of paediatrics, health promotion and women’s specialist treatment.

Australians also noted the importance of grassroots advocacy in the beginning, and characterised the relatively small group of initiators as having both ‘passion’ and ‘determination’ (BP0323), with the keenness to promote support for families as instrumental (BP0323, RS0327, RS0331). The ‘tough’ start for early advocates was acknowledged, as was the momentum which was gained over time

(RS0331) as researchers joined with parent advocates in Australia (MD0326). The significant contribution of ‘a number of Aboriginal people who have been strong advocates in their communities’ was recognised (RS0330), as was ‘the voice of articulate, affected adults (parents)’ which ‘changes the argument, helps push this issue, in the media’ (RS0331).

So, it comes down to better detection and recognition of the longer term impacts coupled with articulate mothers through the media. (RS0330)

In the United States, promoting public interest was reported to have been generated through the personal story of Michael Dorris in 1989, which was a catalyst for other parents to tell their stories over the next four decades. The ‘real people with real stories’ brought balance to the information and advancements provided by scientific research (NG0111). Birth parents like Kathleen Mitchell, who is the Vice President of NOFAS, are advocates and a strong presence in international forums, sharing their personal stories. Birth parents are claimed to bring a different and ‘authentic’ dimension to fetal alcohol and FASD prevention (BS0103) and to engage with the media (ET0112). ET0112 claimed that parents and carers, regardless of role or status, are those most able to demonstrate knowledge ‘beyond rhetoric’ and articulate the potential for those living with FASD to live meaningful and fulfilled lives, sharing support strategies often self-taught from their lived experience. Birth mothers in particular, who were thought to be most important, were ‘able to tell their stories in a believable and accurate way (it is important they come across as mainstream-everyday people)’ (BP0109).

These are the individuals and families directly affected by FASD and the parents are ‘not necessarily biological parents’. (BS0103)

Canadians named key advocates like Audrey McFarlane from the Lakeland community in Alberta, who promoted provincial political awareness and understood that ‘issues and solutions are critical at local, provincial and national levels’ (GP0215); politicians were targeted with information and if interest could not be secured, then attention turned to their spouses (SP0222). One Canadian claimed that at a local level, and over time, educators emerged who were able to speak publicly about the permanency of ‘brain based birth defects’ and that the knowledge and understanding this group imparted about addressing the problem on multiple fronts was later invaluable at a national level (LP0219). The Federal government concurred, with recognition that multiple systems needed to be part of the solution and that it was not just about health services (RS0217). As a consequence, issues and solutions were understood to be ‘critical at local, provincial and national levels’ (SP0222); another Canadian agreed: ‘local people powered groups are best’ (LP0219).

As another example of parent resourcefulness, one Canadian outlined the formation of the Fetal Alcohol Support Network in the eastern provinces of Canada in 1991. This initiative was led by Val

Surbey and other parents who were raising children with FASD (BP0220). The Network built and shared a wide collection of resource and reference information, including what had been learned by parents from personal experience. The information was compiled into a free-form database that published FASD information to assist other parents and professionals. A listserv discussion forum began with funding support from the Canadian Centre for Substance Abuse. The information exchange offered was identified by one Canadian as the ‘most influential single force’ in prevention that identified a turning point in ending the media’s and academic institutions’ control of access to information (BP0220). Similarly, international development (MD0326), technological advancements (RS0330) and the usefulness of Canadian knowledge, information and resources were beneficial to advocacy efforts in Australia (AP0332).

NOFASD Australia’s founder, Sue Miers, had gathered information from personal research and with the support of a small group of friends formally established the non-government entity (BP0323; RS0327; RS0331). Other parents joined the organisation (birth parents) to influence health professionals through collaborative and persistent effort (RS0327, AP0328). With their interest in FASD research secured, Professors Carol Bower and Elizabeth Elliott supported the aims of NOFASD Australia and later achieved status as the authoritative medical and research academics in the field of FASD in Australia (AP0332).

For one Australian parent, progress was personal and required a different kind of persistence:

Our attitude towards our son and others affected by fetal alcohol exposure has changed and we have developed patience and understanding. The biggest question is working out what is bad behaviour and what is FAS. The extended family has learnt to cope with our son’s behaviour and how to ‘manipulate’ the situation and divert his attention. There is no one to give us a rest, to step in and give us a hand. The awareness of service providers has improved and it took a long time for the paediatrician to acknowledge that fetal alcohol exposure was the cause of our son’s disabilities. (AP0328)

One Australian commented on the role of NOFASD Australia and spoke of the struggle ‘to attract champions to the cause of FASD prevention without meaningful exchange from those who could change the world for those afflicted with FASD’. This same participant clarified that no-one in Australia could really ‘make substantial change’ in an environment of ‘ignorance, fear of stereotyping and the implications of FASD’ (RS0325). One respondent suggested that leadership in Australia is best left to a ‘critical few’ from obstetrics, midwifery, research and advocacy groups (RS0330), while another discounted any leadership from within general health areas (RS0330). The absence of an ‘influential national organisation’ in Australia limits the opportunity to ‘garner support from a range of

mainstream services’ and to then co-ordinate better responses ‘on a range of alcohol problems’, suggested an Australian participant (RS0330).

Parents are effective leaders and authoritative but ‘how do you find me?’. (AP0328)

8.2. CO-ORDINATION AND COLLABORATION

As in Australia, in the United States the importance of the collective voice was deemed critical. One participant noted that individuals might rise above others into leadership roles, but their work should not be ‘defined by professional role or status’ (ET0112) because it is complemented by ‘boots on the ground’ to sustain change. Similarly, in terms of prevention, there is never a single source and progress will need a collaborative effort (BS0103). As one Canadian noted, ‘If we don’t collaborate, we don’t get the bigger picture’ (RS0108).

Multiple responses to FASD across different disciplines were reported by Canadians. The FASD Cross Ministry Committee in Alberta has been very effective at the highest level of government, with representation from different ministries who would have some responsibility in responding to FASD keeping the issue on the table. What works is consistent meetings, considering the impact of FASD across different systems, and allocating resources to respond to identified needs (RS0214). The Canada Northwest FASD Partnership has been ‘authoritative’ and ‘the primary driver’ in terms of keeping these concerns to the fore (RS0214). The work of Dr Sterling Clarren in collaboration with Jan Lutke was identified as helping to move the issues forward nationally and internationally (RS0214). Nancy Poole and Amy Salmon, co-leaders of the NAT on Women’s Determinants of Health, were also identified as significant leaders, particularly in relation to prevention. The members of this NAT are reported to be engaged in outstanding research and community services, and supports to women in the interest of prevention (RS0214). While one Canadian expressed the view that inter-sectoral collaboration is critical in responding to the complexity of FASD (RS0214), another felt everyone is ‘at the same table and dedicated’ (RS0217).

I believe that medical and social science researchers have most reliably brought this information to the attention of policy makers and the public (RS0214).

Major institutions involved in advancing the fetal alcohol policy agenda in the United States were frequently named as most influential in bringing attention to the problem of FASD. The Center for Disease Control was described as presenting a public health perspective on FASD, and reported to continue to be a ‘primary driver’ in FASD prevention and better funded ‘to undertake surveillance’ because of the ‘need to know what will make a difference’ (BS0103, MD0107, BP0109). The Substance Abuse and Mental Health Services Administration (SAMHSA) was named because of its

interest in successful ways of working with people, and for sponsorship of the FASD Center of Excellence (BS0103, MD0107) which during its formation in 2000 included participants in listening circles who were family members, tribal people or service providers (HP0106). The Health Research and Services Administration (HRSA) represents the ‘uninsured, isolated or medically vulnerable’ (RS0105), and another important and influential organisation is the Indian Health Service (IHS). Even though research is not part of its mandate, the IHS relies ‘on research undertaken by other organisations’ such as ‘the Native American Research Centers funded by the National Institute of Health’ (MD0107).

In respect to First Nation people and their cultures as a positive influence, one participant from the United States commented that the presentation of FASD in First Nation children, and increased awareness of the problem and its prevention, led to communities taking ‘direct public health action’ (BS0101). In Australia, some Aboriginal parents were perceived to be ‘brave enough to advocate’ for change because of the burden of ‘intergenerational use of alcohol’ (RS0325). One of the great things to happen was the leadership shown by Aboriginal people from the Fitzroy Valley. This group lobbied the WA Licensing Board and were successful in limiting sales of full strength take-away alcohol, limiting alcohol consumption in those communities. This was mentioned by Mick Gooda (Australia’s Aboriginal and Torres Strait Islander Social Justice Commissioner) in his Social Justice Report for 2010: an entire chapter is dedicated to issues relating to alcohol misuse and identification and diagnosis of FASD, and demonstrates the impact of lobbying by this community (MD0326).

Since 2001, collaboration in the United States between NIH, NIAAA and SAMHSA ‘has built some traction and attention for women, children and families’ and works with the not-for-profit sector including ‘NOFAS; drug advocacy groups and expert panels (including researchers, affected individuals and those in recovery’ (MD0107). The ICC-FASD in the United States is influential ‘inside’ government, able to ‘bring agencies together’ (HP0105) to promote expert liaison across professions including obstetrics and paediatrics and link with non-government organisations like NOFAS (BS0103). NOFAS is the national peak non-government entity, reported as instrumental in the education of federal policymakers, the state affiliates who train others to advocate to state legislators; NOFAS ‘has written most of the language that has resulted in government agencies receiving FASD funding’ (BP0109).

Policymaker interest was attributed to the huge cost of caring for those living with a FASD in the United States. Most of the cost came from public funds, and the fact that most legislators can understand that FASD ‘increases utilization of nearly all state or provincial service systems’ makes FASD competitive as an issue worthy of policy attention (RS0108).

Federal agencies engaged in the issue through the ICC-FASD and standing members reported back. This effort was the foundation of bringing federal agencies closer together; funding for work to be done was achieved. ICC-FASD is required to report on programs and working groups on strategies and achievements. (BS0103)

Australian participants detailed the key turning points that marked the worthiness of FASD as a policy issue in Australia. The first was the establishment of the Intergovernmental Committee on FASD as ‘an outcome of the ministerial council for the drug strategy’ that brought together clinicians, researchers, policymakers, big alcohol, research institutes and government representatives (state and federal); a monograph was written. The second was the numerous presentations made ‘about FASD to medical and lay groups’ (MD0326), from which arose the entry of medical professionals and research; this meant medical involvement came to the ‘forefront of clinical care and knowledge’ (RS0330). The third point was the establishment of FASD Data Collections and the National FASD Resources Project which aimed to determine ‘what data about FASD’ and ‘what data on alcohol use in pregnancy’ should be routinely collected (MD0326). The fourth factor was research. The University of Sydney Medical School, the George Institute for Global Health, the Nindilingarri Cultural Health Services and Marninwarntikura Women’s Resource Centre are an example of collaborative research in the Fitzroy Valley.

Even though NOFASD Australia was regarded as the peak body representing the interests of individuals and families, the absence of a national organisation to influence the FASD prevention agenda at the highest level (RS0327) was regarded as a limitation. Partnerships of parents, professionals and ‘experts’ in the FASD field provided a national platform for parents to keep prevention on the agenda at the highest level in the future, argued one participant (RS0327). Others somewhat agreed. Peak bodies needed to grow, with representation in all states and territories. Australia was understood to need ‘full support from professionals, parents, carers and sufferers’ (BP0323) and governments across all systems (MD0326). It was suggested that such leading entities would identify emerging trends and unmet needs for those living with FASD and identify these might be addressed in a national, strategic, multi-sectoral approach within the National Drug Strategy. Such an approach would gain support from the Public Health Association of Australia, various professions and their respective training colleges (RS0327).

Conferences continued to be instrumental in drawing people from around the world to consider this issue ‘in an enlightened fashion’. Medical science researchers had shared their knowledge through venues such as these conferences, and over time, but ‘the domination of medical knowledge has given way to more inclusiveness of social science research and this is critical in moving the agenda forward’ with the Institute of Health Economics Consensus Conference on FASD in Edmonton, Alberta 2009 noted as ‘a crucial event in terms of identifying the need for consistent approaches to policy that

consider the lifespan of the individual with FASD' (RS0214). However, other participants felt there was a 'lack of co-ordinated leadership' in Canada (AP0213; AP0216). Invitations for inclusivity are countered by an 'unwillingness to share resources' (ET0221). Within the FASD network were 'underlying loose cannons who can mess things up quickly' (AP0213). There was no one designated spokesperson (ET2021, AP0216) as all were 'engaged' and it was no longer limited to just a few (AP0216); one participant thought FASlink 'can speak the truth and not be bullied by political correctness because neither the alcohol industry nor the government provide funds' (BP0220). One Canadian participant expressed the view that there were no leaders, and that even 'the charismatic leadership of people like Sterling Clarren' could not be heard 'against the cultural war' of conservative politics that 'pander to the lowest common denominator' (LP0219):

Various individuals may continue to be actively involved in advocacy however the momentum is small. (LP0219)

In the United States 'many prominent persons ... who champion the causes and prevention programs' stood out (BS0101; NG0111; MD0107). Describing ideal leadership as 'a collection of diverse voices ... creating a gestalt, a holistic understanding of the issues and implications' in different settings, one participant noted rare instances of elected officials showing leadership (ET0112) while others noted little leadership (MD0102), particularly at a national level (RS0105). Different people 'in different areas' were described as having specific authority on aspects of FASD in Australia by some (MD0326; RS0327; RS0331) while others thought authority was 'held by academics' like those from the Telethon Institute (BP0323; RS0325) or Elizabeth Elliott (RS0325; AP0332). These people 'have credibility and an evidence base' unlike grassroots knowledge, which was not accepted even though it was grounded in practice, wisdom, strategies and interventions (BP0123). Some were thought to have leadership in their field through 'advocacy, presenting and publishing research results' while others offered 'lived experience' as parents and carers of those living with FASD (RS0327; RS0331).

There might be collaboration, but a lack of coordination in the United States (NG0111) was noted. For one Canadian the current situation was somewhat divisive when once there was 'equality' (AP0213), while for another it concerned the different approaches used in different provincial and territorial jurisdictions (RS0214). The following example was noted by a Canadian participant:

Recent research in the paper re minimum alcohol resulted in 20 different articles in the newspaper. All came out to reject this research and messages were the same. No co-ordination (AP0216).

8.3. FOR THE LOVE OF ALCOHOL

The impact of FASD was expressed by an Australian participant to have ‘hit critical mass’ with multiple issues to consider (BP0323). The first was identified as government, and in particular the issue of decision-makers’ understanding of FASD and how this had ramifications on funding. Governments were considered to first ‘consider voters, how many people drink’ (BP0323), which weakened the determination of some Australian state governments in opposing the alcohol industry and displayed ‘a total lack of will’ (AP0332):

We stigmatise FASD and live in a culture of denial. (MD0107)

Several other Australian participants indicated concern about the alcohol culture including ‘the power of the alcohol industry’ (AP0328, AP0332), which was proposed as ‘almost stronger than the power of government’ (SP0329). Government was thought to be under pressure from the alcohol industry (BP0323) and alcohol products enjoyed ‘special exemptions from food standard laws’ and the labelling of product contents (RS0325). The alcohol industry was claimed to have ‘a vested interest in FASD’ (RS0325) yet it took no responsibility for alcohol products or harms caused (SP0329):

Alcohol is so impregnated into our culture – the weekend binge; its part of the lifestyle; its all soaked into the culture including using alcohol to self-medicate with anxiety and stress (SP0329).

In the United States, the alcohol industry and its allegiance to the value of supporting alcohol use as a ‘cultural norm’ was considered to exert economic power and influence; the industry was not ‘keen to acknowledge the social problems associated with products or influence sales and profits’ (RS0105, ET0112). It was claimed that the taxation revenue from the industry of \$3.2 billion did not balance out the \$50 billion in damages from alcohol harms and governments didn’t want to put the public ‘offside’ (BP0220). For a Canadian, the alcohol industry was seen as offering some support for a number of prevention activities (GP0215), while others claimed the industry continually thwarted progress (LP0219; BP0220) through donations to politicians (LP0219):

reality is that if we drink more, there is an increased harm in all areas. (RS0330)

One Australian agreed with this point (RS0325). The alcohol industry was considered to be vigilant in countering the scientific evidence (RS0331) or in opposing any increased alcohol taxation or labelling on alcohol beverage products (MD0326), and offered no warning or statement of teratogenic risk (SP0329). The Australian policy context was ‘a failure to capture FASD as one of many alcohol related harms’. This policy was based on a perception that the incidence of FASD is not as high in

Australia as in North America, a predilection to focus on FAS only and therefore only on high-risk drinking in pregnancy, poor evidence of risk except in Aboriginal communities which support a ‘no problem’ attitude of the risk to the general population, and a population health focus on illicit drug use (AP0332).

One Australian interviewee highlighted the story of the Fitzroy Valley, Western Australia. The alcohol industry opposed support for change to restrictions on the availability of full strength alcohol, and the success of the community in achieving change left the ‘police concerned that the industry will prevail’ at some stage in the future (RS0331).

The biggest impediment is government – Federal and state. Until about 18 months ago, they simply did not get it. There have been huge changes in the past 18 months but the government ‘rests on its laurels’ on the back of funding for Telethon research and there are still no services for people affected by FASD. (BP0323)

Some Canadian participants suggested that ‘the love of alcohol’ (AP0316) and the alcohol industry’s ‘vested interest’ (AP0213) perpetuates ‘massive denial’ of the problem and creates ‘ambivalence about alcohol’ (RS0217). On the other hand, Canadian breweries ‘provide Sick Children in Toronto funding for research’ (AP0216). This same participant noted that the alcohol industry in Canada does not have ‘the same power as in NZ, perhaps Australia’, as the Canadian government ‘controls liquor’ and yet, ironically, Canada does not ‘have warning labels’ (AP0216).

The notion that ‘no-one has an alcohol problem’ and the personal discomfort invoked by FASD means people ‘don’t talk about it’ (BP0320). While a Canadian suggested people want ‘to convince themselves that alcohol and drinking is OK’ (SP0222), an Australian participant expressed the view that government ‘wants to keep a lid on the problem’ and ‘hope the problem goes away’.

The government is convinced that kids get picked up in the system anyway and don’t want another complex problem to deal with. It is easy to mask the problem as the science is not solid and the seriousness of FASD cannot be demonstrated with recorded data indicates low rates of incidence (RS0331).

As a Canadian participant pointed out, ‘If the problem is too big, it has no solution. If the problem is too small as the alcohol industry would prefer to claim, then no solution is required’ (AP0213). For another Canadian interviewee, the least point of influence on building the fetal alcohol policy agenda was described as warning labels on alcohol beverages:

I have noticed liquor commercials – hard liquor has replaced beer ads during sporting events on TV. In general, I think there is societal awareness of the harms of alcohol on health (RS0105).

Alcohol use in the United States was influenced by economic, social, political and cultural factors (BS0101) and yet disability policy, for example, reflects the risks of illicit drug use, not alcohol; ‘the thing is, you can’t find people who use illegal drugs who don’t also drink’ (CH0104).

In respect to the cultural context of alcohol use, shared values and beliefs about alcohol ‘define problem definition and no solution’ advised a participant from the United States; this translates to professional practice because alcohol use ‘evokes strong feelings’ from personal experience bound up in fear and trauma, with ‘few seeking healing and recovery from addictions’. Teachers, legislators, doctors and social workers ‘drink too’, and denial is ‘well-defended’, perpetuating the status quo (ET0112). This same point was made by an Australian who felt that the culture of alcohol sees wine portrayed as having ‘health benefits’ and regarded by elites as a ‘sacred cow’, as ‘health professionals also drink’ (AP0332). Another Australian spoke of a ‘general complacency’ and ‘self-serving optimism’ of risk for the individual but not for the community. In effect, said this person, ‘their problem is not mine’ (RS0330). As a Canadian pointed out, the biggest challenge ‘will not come from the alcohol industry but will come from ourselves’ (AP0313).

An Australian participant paid attention to the power of language concerning alcohol. People ‘distance themselves from risk’ and use terms like ‘abuse, misuse, it is way in which we can say ... I’m not like that, I don’t abuse alcohol, so I’m OK’ (RS0330). In research, the challenge is how personal alcohol use is rationalised, advised this participant:

If we ask someone what a risky drinker is, or a heavy drinker, you can expect it will always be someone who drinks more than them. Some research on the willingness of midwives to intervene in smoking found two main influences, (1) whether the midwife smoked; and (2) what their manager thought about the relevance or importance of intervening (RS0330).

A bias inherent in the alcohol policy was reported by a participant from the United States to exist ‘at the interface of US government legislation and the ideal of maintaining freedom of choice’ (BS0103). Less government involvement in people’s lives ‘is a current policy theme’, and there is ‘a tension between government legislation and personal behaviour’ (BS0103, RS0105). Alcohol policy is reported to be fuelled by public suspicion so that any policy proposal which seems to intrude on individual choice leads policymakers to balance individual choice with the objective of ‘public good’ – and you cannot oppose the alcohol industry (NG0111). This policy position is exemplified in the United States Surgeon General statement which ‘sets a standard’ which is discounted by the ‘popular

media'. Somewhat ironically, there are people who dismiss the science although 'policy is informed by the science' (ET0112).

As specific examples, two pieces of United States legislation were highlighted. The 'Individual's Disabilities Act and the Child Abuse Prevention and Treatment Act, Part C' documents findings on 0–3-year-old children with developmental delays. In 2003, 'attempts to modify the legislation resulted in a change which proposed all child subjects of substantiated child abuse are at risk of developmental delay'. The legislation included references to illegal drugs but specifically not alcohol. The participant considered there were 'reasons alcohol was not included' (CH04).

The absence of acknowledgement of social problems associated with their products was suggested as part of the government agenda, given the power and influence of the liquor industry (ET0112). For one Australian, the alcohol industry was 'subversive' (BP0323). One Canadian identified 'surreptitious monitoring' of FASD activities as ongoing (BP0320). The attitude to alcohol was to minimise potential harms, but shared warnings about alcohol use was viewed as contrary to the popular drinking culture. The low dose risk issue prevailed (RS0325):

What advice can be given? If this was any other drug, what would our advice be? We wouldn't have the debate. (RS0330)

In this context, the United States government's role in FASD is proposed to be 'formidable' given 'the tremendous income' from alcohol taxations (ET0112). For a Canadian, the payment of \$3.2 billion in alcohol tax is little when compared to the cost of alcohol related harms, estimated at \$50 billion a year (BP0220). Therefore, it was felt, FASD was not a popular problem to be associated with for policymakers (RS0105).

According to two Australian participants, the alcohol lobby and the social and economic 'set up' value alcohol (MD0107), and the fact that people 'do not want to see the negatives of drinking' was evident in the absence of labelling alcohol products with warnings (BP0323).

At a time when alcohol is becoming increasingly available there will be an increasing prevalence of drinking by many in society including young women. It doesn't matter how many brief interventions are in place, if we allow increasing alcohol consumption there will be an increase in health concerns, e.g. breast cancer. Young women are drinking like never before and this will lead to a range of health concerns (RS0330).

8.4. SOME GIRLS, SOME WOMEN, SOME MOTHERS

Girls and women who use alcohol (or other drugs) in pregnancy are not a heterogeneous group. Some girls and women are viewed as deviant because they drink; others are not. Some girls and women who are pregnant are viewed as deviant because they drink; others are not. Left unaddressed, girls and women as parents continue to use alcohol, perhaps increasingly across subsequent pregnancies and with a more pronounced risk for as yet unborn siblings. Left unaddressed, the social use of alcohol in pregnancy becomes normative. Myths which support continued alcohol use in pregnancy are perpetuated and often supported by biased 'scientific' evidence which is at odds with rigorous research-based evidence.

Although not within the scope of this research, the concept of gender as a socially constructed phenomenon undeniably dominates thinking about 'who has the problem'. Gender emerges in the interview data and in the events described in the stories from the three countries as a site of stigma and discrimination, and as a factor in the clash of divergent values and beliefs about problem resolution. Likewise, socially and culturally accepted patterns of alcohol use have not altered. Reducing the harms caused by alcohol across the social spectrum is underpinned by a medical model authority. For those we might call 'good drinkers', youthfulness and peer pressure may be claimed as causal and harm minimisation policies are predominantly grounded in personal choice. For older people who have developed a dependency, a disease model is applied and self-responsibility is described as beyond their control. For those who may be called 'bad drinkers', alcoholism is socially constructed as a 'social problem' and the media perpetuate a notion of difference between social groups of drinkers. The fact that alcohol is a drug which affects the central nervous system, altering thought and behaviour, is a source of both amusement and condemnation. It is accepted that alcohol use will be with us; and as no solution is evident, it must be managed. The real problem is that among the 'problem managers' – policymakers and politicians, physicians and clinicians, researchers, educators and trainers and service providers – we also find users.

When gender was raised by a United States participant, it was in the context of recognising all women as 'at risk for an alcohol exposed pregnancy', including 'Caucasian college graduates who have alcohol issues' (MD0107). For one Australian, the importance of gender was realised with the inclusion of women and pregnancy as a set guideline in the National Alcohol Guidelines in 2009 (SP0329); this policy shift was viewed as 'sensible' (RS0330) by another interviewee. Comprehensive care and health promotion needed 'to match the issues challenging women and their general wellbeing' (MD0102) in the United States, while a Canadian participant valued the positive impact of shifting from shame and blame value positions in respect to birth mothers in their country (AP0213).

There are perinatal care issues too: questions about the levels of adequacy of care – no care for the highest risk women and comprehensive support for other women. We have learnt a lot from tobacco use and this could be translated to alcohol interventions. Motivational interviewing has not translated across community settings as opposed to clinical settings, even clinical settings are undertrained in this model (RS0108).

Other Canadians noted that sharing stories on the lived experience of birth mothers (AP02313; AP0216) had translated into community work underpinned by social determinants of health approaches in policy and practice (AP0216). ‘Teenage mothers are not the biggest problem, rather it is women birthing their 3rd child who are at much greater risk (RS 17)’; and a woman ‘in the severe stages of addiction’ was proposed as in the most difficult situation to overcome in the future (ET0221).

Current thinking ‘locks women into a harmful place’, advised a Canadian (AP0216), and women’s health in Canada is ‘not on the table like in Australia’. Non-government clinics and advocacy efforts from within the medical system and the Centre of Excellence in Women’s Health in Canada were reported to be trying to ‘promote less profiled women’s issues’ like trauma and the association with alcohol use in pregnancy (RS0217). Yet in one Australian participant’s opinion, women are not asked about their alcohol use at antenatal visits, and when information is provided on the risk of alcohol use in pregnancy, it is ‘incomplete’ (AP0332).

Research in the early 1990s in the United States looked at how many women were drinking, and how much, and this raised media attention and public concern. ‘The media were able to continue on that theme’ (RS0105), and it was deemed important to conduct ongoing research on ‘how many women were drinking who were not pregnant so that women could be reached upstream’ (BS0103). In all three countries, women were shielded from the possibility they might harm their baby (BP0220; RS0108; AP0332) and from any perception of personal guilt (SP0229). The failure to identify ‘alcohol use in women and prenatal alcohol use’ compromised prevention efforts in the United States (RS0108). One Australian claimed that the stigma associated with FASD was deemed a worse outcome than the disability (AP0332).

While a United States participant advised of some level of physicians’ awareness in their conversations with women (RS0105), another advised that CDC studies have found ‘approximately 1 in 2 childbearing-aged women report past-month alcohol use, with 1 in 8 reporting binge drinking’; this finding has remained stable over time. Estimates women aged 18–44 years having had one or more drinks during the previous 30 days ‘ranged from 20.4% in Utah to 68.4% in Wisconsin’. Patterns of binge drinking defined as four or more drinks on any one occasion in the last 230 days showed prevalence estimates ‘from 6.5% in Utah to 23.9% in Wisconsin’ (MD0107).

Messages of risk are delivered with discretion or perceived as irrelevant. As an Australian pointed out, young women may be given advice about alcohol use in pregnancy, but claim this advice is irrelevant as they have no plan to become pregnant (RS0330). For Canadian participants, the messages given to women may increase discrimination (GP0215), and so FASD has become a racial issue which has given scope to 'the middle class' to deny their patterns of social drinking as risky (AP0213). 'Stigma is social' proposed a Canadian participant (AP0216); and in the United States it 'stigmatises the birth mother' (NG0111).

Whether culturally or gender based, maternal care practices were noted by a United States participant as increasingly 'medicalized' (MD0107). Both a Canadian and a US participant pointed out that a challenge for the health care system lies in identifying 'women who typically are not accessing services' and 'actual women at risk for FASD' (RS0108, SP0222), rather than women who are easily accessible for research studies (RS0108). Screening women for alcohol use 'has not translated to all settings', advised a participant from the United States (MD0107); and in Canada there is a 'lack of standards and consistency in interviewing women' in respect to substance use in pregnancy and the screening tools used are 'intimidating' (ET0221). FASD support services need to be targeted 'at clinics where women are going' advised a participant from the United States (BS0103).

A tension arises in the dyad of children's and women's health. Attention only to the child is based in the notion of child as 'innocent', which means the mother's 'guilt is the default position' (RS0217). Support systems in Canada are structured on this dominant belief; however, as the child's needs are met through the parent, the parent must be considered too (RS0217). An alternative is needed to the adversarial approach made to Canadian parents that 'this is what you need to do to get your children returned' (CH0214), one that does not threaten separation. Resources should be invested in parents to overcome processes which are both 'adversarial' and 'misogynist' (RS0217).

The current approach to program delivery, policy, resource allocation and legislation in the United States reflects contemporary knowledge of fetal alcohol exposure and FASD as well as of contemporary values and belief systems (ET0112). In Canada, stigma and a lack of safety for women disclosing alcohol use makes diagnosis and research difficult (RS0217). For this reason, it was claimed, stigma is created by professionals who make judgments about women (SP0222). As an Australian participant describes from her personal experience:

I am an adoptive mother and have no real idea how it might be for a birth mother. I think it would be different, there would be stigma. I think that if I had been able to fall pregnant, it could easily have been me that gave birth to a child with FASD. I can remember when we going through IVF and there were 14 women in the IVF Clinic and a pub down the road. We would share wine and none of us knew the risks. (AP0328)

An outcome of the diagnostic process is a focus on the child, with no attention to the mother. This was claimed to lead to moral stigma, blaming and shaming mothers, which did little to encourage them to seek help (SP0218). To build better outcomes for a child and their family, a social network of paraprofessionals working with respectful approaches was needed (RS0214). In the opinion of one Canadian participant, the problem was compounded by ‘academic versus parent’ approaches, and there was no conversation (AP0213). The perception still exists that women would be blamed and children couldn’t be helped (RS0331).

For Canadians who mentioned women as a target for future prevention policy initiatives, there was a need for ‘a continued emphasis on addressing the broader determinants of health’, with program development based on client’s definitions of what worked for them (SP0218) and acknowledging their journey in life to create safe conditions for disclosure about their drinking (ET0221). This kind of approach is ‘client centered, non-judgmental and respectful’ (SP0218) and includes ‘the use of subtle messages’ to invoke thinking about choices women face. Likewise, Australians who spoke of gender identified ‘living in a safe environment’ as a fundamental first step so that a woman could tell herself, ‘I have to plan to be healthy before I have a baby’ (RS0325). Mentoring programs like the Parent–Child Assistance Program for women at risk for an alcohol-exposed pregnancy was proposed as an example of what might be implemented (GP0215):

The ambivalence about alcohol, about women’s equality versus the rights of the child and a medical model versus a biosocial model underpin medical practitioner’s attitude and attention to FASD (RS0217).

For others, the issue of gender drew commentary on the global absence of best practice that is gender specific (MD0107). In the future, women must be provided with ‘medically accurate information on the possibilities’ for prevention (ET0221).

Participants from Australia thought minimum data sets for recording and reporting alcohol consumption in pregnancy should be implemented (RS0327, RS0325) and future policy in respect to women needs including ‘a comprehensive approach to supporting healthy pregnancies’ and ‘early education in schools targeting young women’ as important components (MD0326):

I said to my mother, thank goodness you never drank or where would I be, how would I be coping. I choose not to drink but it is astounding how much pressure is applied to taste this or that wine. Someone was telling me about a baby shower she attended and many of the women were pregnant. Ten bottles of champagne were provided and all were drinking. There was an argument that the champagne was low alcohol. (RS0331)

8.5. FIRST NATION AND ABORIGINAL PEOPLES

There was a need to consider patterns and social norms of drinking with a greater focus on issues at a local level, particularly on reservations, and women would make a difference in First Nation communities in the United States because the matriarchy would pass on information ‘in a more spiritual way’ (MD0107). In Canada, ‘Aboriginal people have accepted’ that alcohol use causes a great many problems in their communities, but this reality had not been accepted by non-Aboriginal people, so Aboriginal people ‘get painted with this problem when in fact it is everywhere’ (SP0222). An Australian spoke from professional experience:

My people are still ignored. An example is a brochure released in 2001–02 on Indigenous women and drinking. When I asked about consultation, it turned out one Aboriginal woman was consulted yet I facilitated the first workshop in Arnhem Land with an interpreter ... What more do I have to do? (BP0325)

According to a participant from the United States, by the 1990s there were ‘cultural and political developments as well, particularly in Indian Country’, as tribal service providers and communities became increasingly aware of the numbers of indicators observed in children that ‘were directly related to spectrum disorders’. The problem was recognised as ‘completely preventable’, and the severity of the problem and the long-term, chronic effects were acknowledged. These communities took ‘direct public health action to reduce rates and prevalence’ (BS0101). Project Choices (MD0107) was launched, an ‘upstream intervention in Indian country’ (RS0105) to teach practitioners brief intervention skills using specific education resources to prevent alcohol-exposed pregnancies among women of childbearing age in special settings (MD0107). The inclusion of a motivational interviewing approach, of the need to identify women at risk for alcohol use in pregnancy but also to discover from women what is not working for them and identify other strategies in their change plans, was an important step (RS0105):

Project Choices is about trying to prevent developmental disabilities or prevent the pregnancy. It is not telling women what to do but a dual thing. The choice is personalized – prevent an alcohol exposed pregnancy in two ways – reduce drinking or contraception. We have found the program is effective with risky drinkers. We aim to reduce both and the intervention achieved both aims. The theory of motivational interviewing is client centered; non-judgmental; for the woman concerned there is self-efficacy and if she wants to do this thing, she has a choice about change (RS0105).

Another participant expressed the view that society labels ‘certain population groups more easily as having a drug problem’ and that it is ‘OK to say that people on reservations or black Americans are

crackheads because these people are not us' (CH0104). Prejudice, stereotypes, bias and judgment are reported to affect both minority and dominant groups (ET0112), and fetal alcohol exposure and FASD are stories about 'historical trauma versus privilege' (CH0104). In Australia, said a participant, 'institutional racism is the reality' (BP0325).

In rural Canada, the social context of drinking in bars influenced the breadth of the problem, and the legacy of residential schools and associated trauma was identified as a significant challenge to change (SP0222); while in Australia a motivating factor was reported to have come from increasing awareness of the repercussions of intergenerational use of alcohol. Intergenerational drinking is a burden that many families carry when they are disempowered and have neither the knowledge nor the inclination to address the impact alcohol use has in their lives. Great sensitivity is needed when that birth defects are evident in some families while other families are 'brave enough to push ahead with getting the messages out' (RS0324). For one Aboriginal woman who was interviewed, empowerment lay in 'becoming educated' (BP0325):

When I began lobbying and advocating on FAS, I was not taken seriously – they did not want to take notice of an Aboriginal woman. It was like the non-Aboriginal government people were saying who gives you the right to speak for others? I asked people what they thought I should do and so I went back to university. I have a Graduate Certificate an undergraduate degree (with Honours); a Masters Degree and I am now doing a PhD. (BP0325)

8.6. THE MEDICAL PROFESSION AND DIAGNOSIS

The medical and health systems were portrayed as vital to problem resolution on one hand, but criticised as failing to address the problem on the other. This conundrum was most evident in the responses from Australian participants, who expressed the view that having medical professionals engaged in addressing the problem of FASD was essential (BP0323; RS0325; BP0325; RS0331; AP0332). One Australian said community momentum had built over the past couple of years, with improved ability to detect FASD in addition to the more obvious features of FAS (RS0330); for another Australian, there was a question why 'medical practitioners [are] ignoring it': their 'official representative bodies need to ask that' (RS0325). The 'medical lobby is too powerful' (RS0325) commented one, and for another, the criticism 'of the hegemony of medicine' was at odds with the necessary involvement of senior obstetricians, midwives and groups like the Australian Medical Association and other mainstream health groups (RS0330). Regardless, as a Canadian suggested, physicians are needed who have the 'particular characteristics of respect, non-judgment and assertiveness' and who have 'knowledge of the brain and assessment domains' (AP0216).

Somewhat ironic is the reliance on FASD awareness prevention, diagnosis and treatment because public opinion is driven by doctors (RS0325) when, according to another Australian participant, a survey of Australian health professionals revealed ‘most do not know how to make a diagnosis’. If doctors did know how to diagnose, then they lacked ‘certainty as to how to care for patients including referral for further assessment’, because there is ‘no specific treatment’ (MD0326). On a personal level, one Australian expressed the view that paediatricians ‘don’t know or understand the conditions or features’ (AP0328) and ‘GP’s provide incorrect information’ (BP0325). Many were concerned a diagnosis would ‘stigmatize patients and parents’ (MD0326). Participants claimed some psychiatrists do not know how to diagnose in the United States (MD0102); nor did most physicians know how to diagnose (BP0220) in Canada. For an Australian respondent, diagnosis was believed to be currently ‘stagnating’ (RS0325).

Advocacy, according to one Australian participant, had not mobilised and governments were thought to be ‘hamstrung by the medical profession’ and ‘frustrated by a lack of interest’ (RS0325). This means implementation of diagnostic and assessment protocols to ‘motivate diagnosis’ and working in ‘diagnostic teams’ (BP0323) with a commitment from the Australian Medical Association and specialist organisations to educate their memberships ‘to shift the mindset on ADHD, autism etc’ (RS0325). Diagnostic coding for FAS in Australia was required (BP0325), with better training in medical and nursing schools (MD0326).

Participants from the United States suggested that coming to a consensus on defining the spectrum (RS0108; NG0111) and presenting FASD ‘as a cogent medical condition and a neurodevelopmental disorder’ (BS0103) were critical in the future. A new diagnostic criterion that was ‘relevant to adolescent and adult outcomes’ which would ‘almost certainly not involve growth or facial features’ (RS0108) was needed to ensure diagnostic accuracy, as FASD is recognised as a lifetime condition (RS0114). This means interventions must focus on the issues ‘that plague adolescents and adults’; currently no funding is spent on meeting the needs of those affected in these life stages (RS0108). As a participant from the United States advised, FASD is more than a medical/health issue and the diagnosis only describes the initial insult (MD0107).

In Australia doctors ‘don’t believe’ FASD is a problem, and their non-acceptance of a condition they know little about is ‘arrogance’ (BP0323). One participant proposed a barrier to be the non-acceptance of training by others outside their own professions, ‘such is the exclusivity’ (RS0325). For others, continued opposition from the medical field was seen as the most difficult to overcome (BP0109), with paediatricians and psychiatrists (BP0323; RS0325) and ‘recalcitrant doctors with vested interests in the alcohol industry’ perceived to be most often in denial (RS0325).

It is about how the powers that be like the medical model and how the health care system is more powerful than other sectors who might speak for others (RS0217).

For one respondent, reactions to addiction and the misunderstanding of physical brain difference as causal to fetal alcohol behaviours in the past covered the spectrum from ‘benign neglect to active persecution indicating shared social ignorance, fear and reactivity’ (ET0112). Understanding of brain dysfunction had evolved over the past five decades and contributed to understanding the ‘neurobiology of addiction’ in respect to parents and the symptomatic neurobehaviour (of the child), which in turn led to different and effective responses (ET0112). In Canada a great deal of research was being done on the brain and there was increasing understanding of brain function (SP0218).

One US participant noted that FASD was not in the Diagnostic Statistical Manual, and as a consequence many individuals remained ‘undiagnosed or misdiagnosed’ and were often ‘labelled ADD/ADHD’ (MD0107). Lack of recognition of the disability caused one Canadian participant to question if some people were disposable (AP0213). The non-inclusion of FASD as a registered disability in Australia was identified as a barrier by two Australian participants (AP0332; AP0328). Currently disability status is ‘dependent on IQ which has very little to do with FASD’ (AP0328). For Canadian participants, the IQ measurement is ‘inadequate and flawed’ (RS0214) and ‘FAS has been called “the orphan group of disability”’ (AP0213). In one Canadian’s opinion, the prevention of fetal alcohol and FASD is ‘tough’, but once the child is born ‘the problem is less medical’ (RS0217). A participant from the United States pointed out that FASD needed recognition ‘under all federal disability-related benefit programs and in all relevant classification and eligibility systems’ (NG0111).

The adoptive population is at high risk (ET0221).

In the opinion of a participant from the United States, FASD was ‘a neurocognitive disability’ and the ‘face’ of FASD led to a failure ‘to understand the global impact of the central nervous system impairment’ (MD0107). For a compatriot, the challenge was in determining ‘how to move away from the diagnosis of FAS and how to develop applicable criteria for the diagnosis of ARND, ARBD and the neurocognitive manifestations of prenatal alcohol exposure’ (RS0108). This same participant pointed out that the minimisation of the spectrum is due to the current dilemma of being ‘trapped in the grip of dysmorphology which is of little use in the majority of cases of FASD’ because facial features ‘predict nothing in terms of effective treatment or prevention’ for individuals across their lifespan, and at the moment we cannot move beyond ‘the typical manifestations of FASD’ (RS0108).

Australians made the point that diagnosis is problematic because the characteristic features are not always observable, there are no biomarkers leading to a minimisation of the complete spectrum (BS0331), and there is poor recognition of the full spectrum of conditions and a focus on FAS only

(AP0332). The idea of ARND was subject to ‘considerable cynicism’ and there were multiple disorders from which to determine which conditions might be attributable to alcohol (MD0326). According to one Australian participant, few general practitioners were known to ‘adopt brief interventions’ despite a ‘dearth of evidence about effective interventions’ in research settings (RS0330). The outcome, said a Canadian, was a selective diagnosis of autism or ADD/ADHD to ‘avoid the alcohol label’ with the consequence of ‘no intervention and/or support’. This equates with further ‘trauma with bad results’ (BP0220).

It is difficult advocating when doctors deny FASDs. I even question myself ... does this really exist or am I imagining it? I question my own intelligence and maybe that is what the medical hierarchy wants us to do. (RS0325)

Ignorance and denial of the problem ‘renders the baby, child or adult with FASD invisible’, stated an Australian (RS0325). A participant from the United States expressed the view that the problem with diagnosis stemmed from a ‘collective unconsciousness’ of physician ‘denial’ (MD0107), while another felt the ‘greatest obstacle’ was a lack of agreement on what ‘the ‘D’s are in FASD’ (HP0106). This participant explained that the ‘D’s are about problems with learning and its associated [sic] with lower levels of drinking. There is no agreement or consensus. Because of this difficulty in diagnosis, numbers of affected individuals cannot be counted and if you can’t count numbers you cannot demonstrate need. FASD is invisible and invalidated’ (HP0106).

Physician ‘disbelief’ that alcohol is causal or that ‘the disorder is problematic’ perpetuates resistance to advising women of the risk of alcohol use during pregnancy, according to participants from the United States (BS0103) and Canada (BP0220). In the United States there is a second consequence in the discretion (open to those women who have the means) ‘to seek alternative conditions’ (NG0111) or for an Australian participant, a bias to ‘meet the child’s needs’ (AP0322). Hence, the response to early detection and diagnosis was identified as a barrier to addressing the issue of fetal alcohol exposure and FASD. As a United States participant explained,

it needs to be constantly stated that the diagnostic criteria do not focus in a meaningful way and are not connected to issues that need intervention or treatment for the individual with an FASD, their family or to the systems of care. This disconnect is a key in the current funding issues, the need for services and what these services should be ... Again, the facial features are not much of an issue in effective treatment or prevention of future problems. (RS0108)

A United States participant pointed out that an increasing number of children and adults who live with FASD are better recognised (ET0112). However, in contrast, a compatriot claimed that the number of cases identified is low if less than two per cent of the 1:100 estimated prevalence of FASD is accepted

in the total population. This situation is proposed to be attributed ‘at least in significant part to the difficulties inherent in the screening and diagnostic process’ and that an increase in the size and cost of a system which ‘is able to diagnose less than 15% of affected people, is too expensive to support for a common condition like FASD’ (RS0108). As one Canadian interviewee wrote in response to the interview questions, world governments ‘still believe that this is a small problem’ (SP0222).

Until they understand the depth of the problem they will likely have superficial engagement. They won’t understand the depth until we have diagnostic capacity so it is a bit of circle we go in. (SP0222)

A participant from the United States advised of the failure ‘to demonstrate the seriousness of the problem and raise attention’ (BS0103). As another participant explained, ‘about the same time FAS became an important health issue, the AIDS epidemic overshadowed all other public health issues’ (RS0108). Just as a resurgence of FASD began, the autism epidemic became the focus of much of the available discretionary spending of state or provincial governments; currently it is the inability of the FAS field to move beyond FAS to the more typical manifestation of FASD, including birth defects, mental disorders, substance use and developmental disabilities (RS0108). One US participant pointed out that autism is referred to as ‘the darlings disease’ attracting a \$30 million investment in autism compared with \$800,000 for FASD (RS0105).

A parent once told service delegates at a conference, ‘You see the snapshot, we see the moving picture’ (AP0213).

8.7. PREVALENCE, COST AND FUNDING

Informed, sensitive and accurate diagnoses were essential for measuring the incidence and prevalence of FASD and securing funding from government. Building an evidence base was further complicated by uninformed service providers who lacked training in recognising and responding to FASD.

The stigma associated with FASD and professional silos and systems are reported to slow down policy development (RS0214).

Described as ‘complex’ (RS0108), there is lack of agreement in the medical system on the fetal alcohol spectrum in the United States (HP0106; MD0102), and as the diagnostic criteria are not meaningful and are disconnected from the issues ‘which need intervention and treatment’ (RS0108), the number of individuals living with FASD cannot be accurately gauged. The ‘lack of incidence and prevalence data’ in the United States (NG0111) and Australia (RS0325) can be rectified with reliable

diagnosis (CH0104; HP0106) this kind of evidence convinces decision-makers (HP0106) to address the intergenerational impact of future exposed pregnancies (CH0104).

In Australia, predicting prevalence rates based on international sources of data leads to ‘no action’ (RS0325). According to a US participant, Dr Sterling Clarren once stated that ‘the actual numbers [of people with FASD] are so great as to be almost unbelievable’. This participant pointed out that ‘the widely-quoted statement that FASD is the leading cause of intellectual disabilities in the Western world is notable since this claim is being made in spite of lack of diagnostic capacity in virtually all countries’ (ET0112). With the ‘recurrence rate’ predicted to be ‘exceptional’ (RS0108), the increasing number of children and adults recognised as having FASD ‘is impossible to ignore’ (ET0112). As numbers of individuals living with FASD are expected to increase over time, so should diagnostic capacity. This was an important consequence for prevention activities as increasing public awareness meant necessary planning for ‘the inevitable stage where identification exceeds capacity to provide support’ (ET0112).

Although service responses and support for individual children living with a FASD were reported to be evolving in Canada and a ‘lot of good work is being done’ because of increased knowledge and understanding of FASD by professionals, an ‘overall applied model does not exist’. Consequently, responses were reported to vary dependent upon the individual worker who was allocated a case (RS0214). It seemed for one Canadian participant that the kind of response was dependent on the individual provider; and whether individual providers had a strong interest in providing ‘good care’ (RS0214).

While there was no indication in responses from the United States that service delivery was improving, a similar comment was made on the need for pre-service training and in-service education for people from relevant disciplines (RS0108). Training was suggested as dependent on ‘funding and resources to keep communities engaged and willing to work towards prevention’ (RS0217). Maternal care practices ‘within a medical/health approach with the early detection of children at risk of fetal alcohol exposure’ was an example of an opportunity to recommend that a parent seek ‘substance abuse treatment’ (RS0108). The reality, claimed another, was that ‘we work with women and support them, but this is not sustained. Relapse occurs’ (MD0107). FASD was proposed as ‘one injustice in society and the child pays the price’ (AP0216).

Most of the funding spent on FASD is treatment of current issues and almost none is spent on prevention of future problems that define the severity of the disorder for adolescents and adults. (RS0108).

While a lack of government funding has ‘slowed momentum’ in the United States (HP0106), most of the cost of care is nevertheless reported to come from ‘public funds’ as FASD ‘increases utilization of nearly all state or provincial service systems’ (RS0108); further, legislators do not understand just how much funding is already related to FASD (RS0108). That being said, one of the biggest impediments to advancing the FASD agenda would be a decision by Congress to stop funding for FASD programs (BS0103). For several participants from the United States, the issue of ongoing and increased funding to deliver prevention activities – community education, interventions and treatment – is critical (BS0103; RS0105; BP0109; ET0112) and the need to develop strategies for obtaining funding with the awareness that this is not new funding, so that there is competition with other advocacy groups ‘seeking to increase their share of existing funds’ (RS0108). One participant likened the problem in Australia to ‘a lot of issues’ and believed the ‘seemingly low prevalence of FAS means it is statistically hard to do research across the general population’. Further, it is so devastating when it happens to an individual, prevalence data reveals the prevalence is relatively low and so evidence ‘needs to be continually presented which demonstrates the numbers affected and the true burden of the problem’ to government as both need ‘improved funding’ (RS0303).

Speaking about the United States, a participant reflected on a government that ‘prioritizes short-term economic gain over long-term social health’ as the barrier to prevention (ET0112). Another US participant spoke of challenges with Congress, as this is where decisions are made as to how funding is allocated. For example, the non-recognition of FASD contributes to a ‘disconnect with congressmen’ and as a consequence, FASD has not been funded or adopted in some agencies resulting in ‘a lot of people labelled autistic who are FASD’ (RS0105). The cost of lifetime care is extremely high, said one US participant, with virtually no investment in ‘meeting the future needs of those affected in adolescence and adult years’. Given these scenarios, FASD prevention should be competitive for funding (RS0108).

For two US participants, there was a tendency for government ‘to fund what was funded last year’ (RS0108) so if Congress stopped funding FASD programs there would be a serious problem (BS0103). One participant thought that government control over funding allocations in the United States was often poorly focused, leading to limited improvements in prevention (RS0108). A lack of systematic education of policymakers and agency administrators meant they tended to see FASD as someone else’s problem (they were interested but usually not willing to take money from someone else to fund FASD activities) (RS0108). It was argued by one Canadian participant that the message to the government needed to be focused on what will advantage ‘future cost savings’; however, British Columbian governments ‘are short sighted (from one election to the next)’ and it was likely that ‘we ... will have little impact on this’ (SP0222). Others proposed that government awareness of the

economic cost (LP0219; RS0214; GP0215; SP0218) of not committing to prevention was a key influence, but there were also other less tangible costs.

I believe the interest is driven by economics. It is very clear that the cost of FASD is very high not just financially, but socially and personally for families, children and society (RS0214).

One Canadian spoke about prevention work as ‘intensive and costly’ and an activity which ‘cannot be done properly off the side of the desk’ and that in some agencies, responses to FASD prevention work was only undertaken when specific funding was provided (SP02 22). A participant from the United States proposed that the numbers of stakeholders willing to advocate ‘have not reached critical mass’ and ‘families are meeting their own needs which means the time available to self-advocate is minimized’ (NG0111). For an Australian, grassroots advocates did not have funding to publish in glossy magazines and therefore could not compete in claiming ‘best practice’ (BP0325).

In Canada, there was an expressed need for legislators to understand how this issue already permeates and utilises resources from most systems, rather than the ‘tendency to throw money at problems rather than improve situations’ (SP0218) and budget cuts were driving reviews to find ‘fat’ so that electoral promises to spend four to five billion dollars on new prisons ‘which ironically are where people with FASD end up (LP0219)’ could be met. Prison building was ‘popular with conservative prime ministers ... and when the economy takes a downward turn, it is not uncommon for prevention programs to get hit’ (LP0219).

For an Australian participant finding funds to put programs together was not easy.

Money is being wasted and I think now that they [the government] know it ... We need to fund proper programs and prevention that instead of setting people up for failure ... will empower and provide people with FASD a solid foundation (BP0323).

There are no specific services for people living with FASD in Australia and little communication in service delivery (BP0323). In the opinion of other Australians, programs were delivered independently across different areas of alcohol harms (RS0330), and this meant that people living with FASD and their families had to seek their own information individually (BP0323):

wrangling based on different belief systems has wasted over 30 [years] (SP0329).

Even though ten-year strategic plans were in place in Canada, government strategic planning was described by one Canadian as having ‘high expectations with little government initiative to support the work which needed to be done’ and ‘most are short sighted (SP0222). This was said to come from a position of ‘conservative politics and a traditional mindset’ (AP0216). Funding was also reported to

‘not reach Canadian grassroots communities’, with no budgets for work at a local level where ‘most of the support work is done’. Further, the allocation of funding was viewed as problematic because it created competitiveness because ‘once the funding begins to flow, organisations jump on the bandwagon and want part of the funding to offer programs’ (AP0213). As a Canadian participant proposed, government was the critical barrier because all the services ‘required for our children are funded and controlled by governments, with bureaucrats as the gatekeepers from Hell’ (BP0220).

Money. Govt has discovered FASD is costing them big bucks ... in many different depts. (LP0219).

The current complexity of FASD diagnosis in the United States was noted as costly, given a prevalence rate of one per cent of live births, when in competition with other conditions requiring government financial investment (RS0108). A US participant said that evidence needed to be continually presented which ‘demonstrates the numbers affected and the true burden of the problem’, and that both need improved funding (RS0108). For another participant, this evidence would produce newsworthy information mechanisms in reporting on breakthroughs (BS0103). For both participants, there was agreement that education was critical; this one felt that many legislators ‘have difficulty in understanding how much of current service systems capacity and funding are related to FASD’ and educating policymakers was a key issue if there was to be improved funding for FASD (RS0108). For another, there was anxiety about whether there would be fallout from a ‘shrinking federal budget’ (BS0103):

The cost effective power of prevention services versus treatment services costs; the need for multimodal approaches to prevention beyond direct clinical intervention to include community mobilisation and public health models for behavioral change. (MD0101)

Epidemiological studies were suggested by an Australian participant as important to inform scientifically on the incidence and prevalence of FASD in the community. This, the participant claimed, was necessary to support the investment of funding, which in turn could raise public awareness and discount professional disbelief of the true scope of the problem (BP0323).

For one Australian, the problem of FASD is so ‘huge and systemic’ that if acted on it would risk government revenue from alcohol. This was why government sustained an ‘ignorance is bliss’ position, a position unhelped by the lack of evidence of FASD prevalence (SP0329). Accessing public funds ‘to do what needs to be done’ is perceived by another Australian to be a challenge for the future (BP0323).

8.8. FUTURE PRIORITIES

One US participant proposed that in the future focus would be dominated by epigenetic research (MD0102) in the hunt for environmental factors which influence individual vulnerability or resilience to the teratogenic impact of alcohol. This participant also identified biomarkers in meconium, which can be measured to deduce the level of alcohol exposure on the fetus, as possibly contributing to early identification of children at risk; therapeutics like choline might aid in ameliorating the toxic effects of alcohol if administered during pregnancy (MD0102). For some from the United States, continued basic research on ‘the effects of alcohol on the unborn, treatment services, prevention models and interventions’ would better explain ongoing prevalence rates, through population based estimates (BS0101); and improved and expanded surveillance, research on ‘mechanisms of alcohol induced defects’ and the search for biomarkers and longitudinal studies would help identify cases of FASD, distinguish it from other conditions, and measure its prevalence (NG0111).

One Canadian proposed more research on the effects of cortisol and stress on the developing fetus would bring evidence to help women and prevent FASD (RS0214) while for another prevention needed to focus on the child to determine how best to block ‘neurological damage’ to fetal development with high maternal doses of folic acid (BP0220). A greater focus on the role of fathers through research (RS0214) was also suggested. Regardless, unless future research had a breakthrough which ‘would have the world sitting bolt upright, our prevention efforts will remain invisible’ (BP0323).

The prevention of fetal alcohol exposure and FASD in the future would be reliant on the support of ‘champions in Congress’ and influential officials inside the United States government, together with greater collaboration across sectors backed by scientific evidence (BS0103). Bills in Congress and greater government interest were proposed by another US participant (RS0105), while yet another expressed the view that advocates and lobbyists needed to learn how to educate decision-makers (RS0108). In Australia participants believed that with the interest of governments in FASD secured, the development of a FASD Strategic Framework to instruct bureaucrats on how to proceed (RS0325) would be advantageous. A ‘call for action’ to form a national organisation was also thought to be strategic (RS0327), together with champions from media, medicine, research and parents/carers groups (RS0325). The problem currently was the absence of government realisation of funding being wasted through program supports which were ineffectual because individuals living with FASD were unrecognised (BP0323).

In Canada, streamlined responses to families (RS0214) would need to be at the forefront of all systems (AP0213), and would then be dependent on inter-professional and inter-sectoral collaboration in order to accommodate responses to the complexity of issues confronting families (RS0214). In the United

States the continued support of major public health institutions was a priority for one participant. The involvement of NIAAA was essential; the CDC would continue to present a public health perspective; and SAMHSA and HRSA would identify and bring successful ways of working with people (BS0103). National and public health campaigns for government needed to be future priorities, raising public awareness and promoting policymaker interest (MD0102).

A 'non-hierarchical approach' was suggested by a Canadian participant as necessary in the future, with a parent-led formal and national organisation (AP0213) with champions well placed to move the agenda in strategic places (AP0216). Likewise, an Australian participant believed a national co-ordinator, a peak body and an 1800 number was justified in Australia and could make a difference (BP0323). In respect to acknowledging the experience of parents, funding for proper programs instead of 'setting people up for failure' might be better understood by policymakers because 'parents know what is needed'. This would empower people and provide those living with FASD a solid foundation (BP0323).

In Australia, the future meant governments supporting legislative action. Ideas expressed for the future included legislative action through mandatory warning labels (RS0325) on all packaged and unpackaged alcohol beverages as a community education strategy (RS0327); the application of volumetric tax (MD0326; RS0327) to increase the cost of drinking; limitations on access to full-strength alcohol beverages (MD0326) and 'enforced stewardship in alcohol marketing' (RS0325). Further, high-risk communities needed support through enforced legislation (MD0326).

In the United States, participants suggested improved front line quality services (NG0111) in health care, training programs and support (BS0103), and building inclusion of 'a FASD agenda in all service systems' (RS0108) to bring greater attention to a range of interventions reflective to related issues across the lifespan (RS0108; NG0111) as a continuum of care (NG0111). For Canadians, progress in the last 20 years was acknowledged, but more needed to be done (BP0220).

The rapid growth of disabling conditions, and awareness of the impact on society means a disability paradigm must be considered as essential to post-secondary education ... in the health professions, social work and psychology should infuse courses on FASD/Disability concerns in their curriculum to prepare graduates for working in this complex problem area for those entering the helping professions. (RS0214)

For an Australian participant, this meant deconstructing the current disability system of IQ as a measurement of disability for those living with a FASD, and proactive rather than reactive programming (BP0323) as an important initiative, while another Australian believed a future

investment in communicating the value of early interventions over delayed interventions would have ‘a better impact’ (RS0330).

FASD was not an Indigenous issue, claimed an Australian participant who reflected on the possible result of screening all women and the results. The ‘numbers in the Aboriginal communities would be very low by comparison. Fifty per cent of women consume alcohol in pregnancy and 95% of these women won’t be Indigenous’ (RS0331). However, prevention in American First Nation communities was believed to lie with women ‘who will make the difference’, with the ‘matriarchy passing the information on in a spiritual way’ (MD0107). Others from the United States believed in supporting women inclusive of addiction treatment (ET0121).

The link between FASD and gender is apparent even though there is no country with best practice, that practice is not yet gender specific and there needs to be future consideration of the patterns of drinking and social norms of women and alcohol. (MD0107)

One Australian claimed that early education in schools ‘targeting young women’ should be considered, while another spoke of a ‘comprehensive approach to supporting healthy pregnancies’ (MD0326). Other Australian participants spoke of their hopes that awareness of the lifetime challenges and economic cost would grow and become part of the education system (BP0320); of massive public health campaigns (RS0325; MD0326; SP0329); and of zero tolerance messages to inform that no amount of alcohol is safe (RS0325) or that risk is dose-dependent (RS0330, RS0325). In respect to parents, there were opinions on much better information being available (RS0130) and for the inclusion of family planning as an important component of FASD prevention (RS0125).

8.9. SUMMARY

The data from these three countries are rich with knowledge and opinions on the status of the problem of fetal alcohol in each country. Some participants spoke of the need for greater clarity in diagnosis as this linked to greater accuracy in measuring prevalence, and determining prevalence provided the evidence for prioritising FASD as an issue for government. Improved funding and an openness to sharing resources, interdisciplinary and cross system co-ordination and collaborative interventions to accommodate the whole family supported by education in medical schools, in allied health professions, in school systems and teacher and law enforcement training, in the courts and the corrections system were all advocated.

Many participants spoke about the acceptance and normative use of alcohol as a fundamental area for redress in the future, with conflicting values and beliefs about alcohol as a problem for a small number of people. While some people called for the alcohol industry to be made liable for the harms caused by

its products, others preferred to consider strategies to address levels of consumption at a whole-of-population level, strategies that reflected communities working out what could be done and driving change. One respondent summarised the diversity of opinions on possible solutions:

We know what needs to be done, can't wait for government to accept this premise and act or go ahead and do the work in community minded ways. (SP0222)

In the following chapter, the similarities and differences in the outcomes of interviews and how these opinions are validated or invalidated in the stories of fetal alcohol in three countries are examined. The analysis of the archival sources of information and data will collectively describe fetal alcohol as an intractable problem. It is to this task that this research now turns.

CHAPTER 9 FASD AND PROBLEM INTRACTABILITY

This research aimed to better understand the progression of FASD from the original demands for problem attention through the public policy process to reach the formal or public agenda. Archival records from events in the progression of FASD as a problem in three countries, and qualitative data from stakeholder interviews, contribute to a better understanding of the positive and negative influences affecting the way the problem is dealt with, explains why FASD is such an intractable problem, and offers some suggestions as to why has there been such resistance in tackling the problem in Australia. Proposals are made on FASD solutions based on the argument that problem intractability is likely to continue because it cannot be separated from the range of stakeholders inside and outside current and prevailing policy direction.

In this research it is argued that as more diverse stakeholders enter the FASD problem system, the definition of the problem and its solution become more contested. Different perspectives may be expressed by those who hold alternative views; but these views may be contrary to the opinions of elites whose technical expertise ‘fits’ the government’s particular policy agenda on FASD. Governments are advantaged, as only the parts of a problem they wish to address are given policy attention, and the control of definitions and solutions for FASD shifts from the demands made outside government to problem management inside government. There are consequences from this for those who live with FASD and their families, as their acquiescence is perceived by those with authority as an indication of their agreement for elites to represent their interests.

9.1. AN AMBIGUOUS POLITICAL PROBLEM

Fetal exposure to alcohol as the cause of FASD is not disputed, but this means that FASD is part of a much bigger problem system – alcohol and its attributed harms. Differences of opinion are noted when it comes to addressing responsibility. The alcohol industry is not sufficiently accountable for its products and the industry is highly influential inside government circles ‘to protect its commercial interests’ (Doran et al. 2010, pp. 468–470). A common criticism from public health professionals is that the industry has been influential in setting the policy agenda, ‘shaping the perspectives of legislators on policy issues, and pushing alcohol policy towards “self-regulation”’ (Doran et al. 2010, pp. 468–470). Any increasing disagreement from the general public over problem definitions or solutions in respect to alcohol use is suppressed with authoritative type strategies. The overall influence of leadership is in some doubt because of the power of the alcohol industry lobbyists and social and economic climates which value alcohol in all three countries. Alcohol is currently a highly profitable commodity and drinking alcohol is a cultural norm, and there seems to be little doubt in the

minds of many of those interviewed that the issue of damage arising has been suppressed by the alcohol beverage industry.

Interview data reveal a greater need for governments to be involved in the solution of FASD; however, for governments challenges are evident. First, governments must manage any perceived public opposition to the 'love of alcohol', as this could cost votes, particularly with the prevention message conveying abstinence throughout pregnancy as the only risk-free option. Second, governments must balance the powerful interests of the alcohol industry and their own need for revenue generated by sales of the product. Third, these problems must be managed against a moral, ethical and perhaps legal obligation to alert their citizens to a major public health issue.

Differences also arise in prioritising public funding for FASD and where it may best be invested. The influence of national institutions has sustained FASD as a health issue, translated as policy-favouring solutions focused on researching clinical intervention and service delivery model outcomes and innovative ways to prevent alcohol use among women of childbearing age. A sharpened focus on alcohol, pregnancy and infant health, which gained momentum in the late 1970s in the United States, has continued with surveys to collect data on women's use of alcohol during pregnancy and funding research into the personal characteristics and life experiences of high-risk drinking women to inform prevention efforts such as Project Choices. Printed and then online manuals with language content linking healthy pregnancy with healthy babies have been repeated in the United States.

Over time the problem for governments has been reduced 'through a carefully structured expansion phase to keep the issue off both the formal and public agendas' and to suppress the demands of the original proponents. The authority to define the problem and provide technical details is limited to the select group, and expansion is contained by limiting it to those groups where consensus with current position is most likely. There are reciprocal benefits of status and funding investment, and whether or not the public policy approach is to invest in research or to target only marginalised communities or some women drinkers, there are consequences to such discretionary policy-making. Government investment in preferred solutions diverts attention to primary prevention and efforts are not concentrated on children and others living with the problem, particularly those older children and adults who have been undiagnosed, misdiagnosed or unrecognised and have no voice.

The Federal government of Canada has had a national FASD strategic plan since 2001, which evolved from best practice research and consultation through stakeholder forums and was reviewed and updated in 2012. The provincial governments of British Columbia and Alberta developed their own FASD action plans, complemented by multiple partnerships across portfolio areas and sectors, based on the early understanding that FASD prevention did not fall within a single policy stream. No similar strategic document is noted in the United States. There, Bhuvanewar et al. (2007) reported, 15 per

cent of pregnant women consumed alcohol in pregnancy. In the detailed findings from the 2011 Australian National Drug Strategy Household Survey, the majority of pregnant women who reduced or abstained from drinking is documented; but half of all pregnant women still disclosed some alcohol use during pregnancy (Australian Institute of Health and Welfare 2011). In the subsequent 2013 report, more than 50 per cent of pregnant women said that they had consumed alcohol before they knew they were pregnant and 25 per cent 'continued to drink, even once they knew they were pregnant' (Australian Institute of Health and Welfare 2011).

Accepting the complexity of the problem and the reliance on changes to belief and culture to foster change, may not be enough: the stories and results of interviews reveal a diversity of opinion about barriers to prevention and what needs to happen in the future, even from individuals who share similar backgrounds and stakes. The role and influence of governments, of medicine and medical professionals dovetailing with both diagnosis and influencing the investment in research, and the contribution of parents/carers in ensuring support and services for those individuals who have no voice indicate how best to manage this problem in the future. In respect to the individual living with FASD, there is a constant theme of the need for consistency in diagnosis. Screening, assessment and diagnosis have been focused on to ascertain and estimate prevalence in both the United States and Australia.

The link between accurate diagnosis and capturing data to estimate prevalence are noted as essential to convince government policymakers of the seriousness of the problem. The development of diagnostic tools in each of the three countries has been independently done and the lack of consensus adds to the conundrum surrounding the identification of individuals recognised at risk for a FASD but having none of the features characteristic of FAS. Reliance on known physical features of FAS (particularly facial features) as a reliable diagnostic criterion for prenatal alcohol exposure has been a driving factor in limiting the accuracy of true FASD prevalence. Secondly, failure to assess FASD, inclusive of neurodevelopmental anomalies in the absence of facial features, avoids naming maternal drinking as the causal factor. Limiting FASD to FAS alone has a major consequence and meant a stronger focus on women and their children in perceived higher risk populations where FAS is more likely found.

9.2. THE PROBLEM IS, FASD IS PART OF A MUCH BIGGER PROBLEM

FASD is symptomatic to at least two larger problems in all three countries considered in this thesis, and these cannot be adequately dealt with in the scope of this research. The first is society's love of alcohol, a health and social issue with stakeholders beyond those revealed in this research. The second is gender, which is defined as a construct of social defined roles and relationships, personality traits, attitudes, behaviours, values, relative power and influence that society ascribes to the two sexes (Chow et al. 2009).

Unfolding events in the stories from each of the three countries substantiates the power of the alcohol industry to influence public policy. There is a much wider band of parties interested in maintaining the status quo than pregnant women who use alcohol – including the alcohol beverage industry, associated businesses as in licensed premises and tourism. Participants from all three countries raised the invocation of legislative supports as critical to future solution attempts, while well aware that governments may not be favoured by electorates if their alcohol policies propose to limit personal choice through the introduction of tighter controls over pricing, taxation, availability and distribution.

The influential power base of the alcohol beverage industry was not lost on interview participants. Alcohol use was described in interviews with US participants as pervasive, multigenerational and socially acceptable. For Canadians and Australians, the culture of alcohol use was strongly felt to be underpinned by denial and general complacency with respect to the harms it causes; and its tendency to distance itself from risk was recognised. The alcohol industry was described by Australians as subversive and sinister (BP0323) while a Canadian associated the perpetuation of alcohol problems with financial gain and marketing strategies that promoted denial on a massive scale (BP0220).

The International Center for Alcohol Policies' *Blue Book* chapter on drinking in pregnancy indicates a steadfast alcohol industry position that only heavy patterns of alcohol consumption are linked to the 'substantial risk' of FAS. The incidence of FASD is claimed to be 'relatively rare, with higher prevalence among particular populations, generally those of low socioeconomic status and who may not have adequate access to care.' A third tenet is to mobilise the notion of the lack of consensus in respect to the lowest threshold to cause a risk to the fetus (International Center for Alcohol Policies 2015).

Public and industry reaction is evident in the controversy over warning labels. A health advisory on alcohol use in pregnancy was introduced to the United States as early as 1977, but of the over 3,000 comments reportedly received, most opposed the warning. Legislators overlooked these challengers and the US Surgeon General's warning label on all alcohol beverages was introduced in 1989. At the time, less was known of the spectrum of effects attributable to prenatal alcohol exposure and as FAS had traditionally linked to excessive alcohol use in pregnancy, it was claimed to affect only a small number of individuals. Science has since revealed a lower threshold of risk for FASD, and this translated to Canada and Australia in terms of unsuccessful campaigns to introduce warning labels. Accepting the scientific evidence of teratogenicity and the toxicity of alcohol on fetal development is unsurprisingly something the alcohol industry would work to avoid.

Legal drugs such as tobacco and alcohol are more widely used and cause more damage, although illegal drugs such as heroin and cocaine often get more attention. Behind legal drugs are corporations that profit from addiction to their products, and they promote and advertise them aggressively

(Greaves & Poole 2007). In Canada the alcohol industry is subject to fairly stringent government regulation and contributes to FASD prevention through joint funding ventures (Canadian Centre for Substance Use) and an annual national campaign. In Australia, the alcohol industry self-regulates its activities, and voluntary labelling to warn consumers of fetal risk was extended in 2014 by the Commonwealth government (Commonwealth of Australia 2014), despite intense lobbying from opponents.

9.3. SOME GIRLS, SOME WOMEN, SOME MOTHERS, SOME COMMUNITIES

The alcohol industry portrays FASD as a consequence of high-risk alcohol use during pregnancy, by women in vulnerable populations. This myth segues into the second large problem of which FASD is symptomatic: gender. The social construction of gender is pertinent when attributing the burden of responsibility for FASD to women, and when the risk of FASD is linked to mothers' feelings of self-blame. This powerful force shapes dominant values and beliefs which, in turn, informs FASD policy target groups. This is demonstrated in the focus of and investment in research in all three countries, aimed at women with the highest risk of drinking: marginalised women. Archival records validate this discrimination by determining predictable life course factors that determine women's drinking patterns, to determine risk and to target activities. There is a well-supported argument that programs should target the most vulnerable and easy to reach women for effective, early interventions. For example, in Canada a systematic study of the effectiveness of prevention approaches which aimed to change drinking behaviour in 'the mother, the child, the family, or the society' by changing information and attitudes to drinking (Ospina et al. 2011, p. 120) found that of the fifty studies reviewed, slightly more than half supported targeting pregnant women; those aimed at a more general public 'were conducted in non-Caucasian populations' (p. 137).

United States and Canadian interview participants linked FASD with stigma for women, some associating the naming of the condition of FASD for a child with stigma for some mothers. The shame apparently experienced by many women who used alcohol did not appear to be such a concern for Australians, perhaps indicative of the relatively new entry of FASD into the public domain. Comments about stigma came from Australian parents who were interviewed, and included criticism that denying a woman's right to be fully informed, either about the risks of alcohol use in pregnancy or later in the process of diagnosing a child, was paternalistic. Service providers in the United States were viewed as denying women information or failing to promote conversations about drinking because of their personal discomfort or fear about discussing alcohol use. One Canadian participant specifically noted that service provision imposes gender-based stigmas. More participants stated that discrimination of some girls, some women and some mothers, particularly in respect to Indigenous women, occurred in the targeting of prevention and research; this was reflected in archival records.

For Australians, focusing on women as mothers who use or used alcohol was not raised as an impediment to these women seeking help, but some US participants mentioned links between focused prevention with women who are more easily encountered in health settings, and the sustainability of funding for program and/or research continuation. For some Canadians, medical professionals' fear of mother-blaming led to their not providing an accurate diagnosis; this had a flow-on effect, as the mothers kept in ignorance did not change their patterns of alcohol use in subsequent pregnancies.

Canadians were most vocal in their opinions on morality-based stigmas, which they felt did not assist in creating safety for women to participate in conversations about their drinking. Other Canadians pointed out that service provision focused on the child living with FASD does not consider the needs of the mother. Blaming the mothers ignoring the fathers in assessment and intervention were deemed misogynistic, particularly when the apprehension of children occurred without investing in the parents. One Canadian complained that screening and interviewing women were done without standard protocols and could be intimidating. There also appeared to be limited research on what actually happens in the longer term to those women who have had an alcohol-exposed pregnancy and are at high risk in the future. One Canadian thought women who struggled with addictions were the single biggest impediment to preventing FASD. The point was made that despite the various attempts to address FASD, the number of women experiencing problem drinking may have increased.

Still on the theme of stigma, Canadians noted a predisposition to blaming Aboriginal families for the problem of FASD, without using an Aboriginal lens or considering how the problem impacted on other cultural communities. For Australians, FASD is also situated as an Aboriginal problem, and a lack of cultural sensitivity in addressing FASD in this population was described as an assimilation approach coupled with 'institutional racism'. US participants did not mention discrimination as an impediment except through the implicit connection between race and condition when defining FASD as a lower socio-economic problem.

In the United States, one participant believed cultural groups needed to accept FASD was a problem, and had to become willing to take it on and address the underlying problem of the pervasive acceptance of alcohol in their communities. These communities had to be prepared to consider the impact of intergenerational alcohol and women's rights, as women were the ones who would be the driving force in creating change at a local level. Archival records from all three countries suggest prevention activities and research tend to focus on reachable women rather than on those who have children diagnosed with FASD or those not easily identified in the health care system.

9.4. SERVICE PROVISION

The approaches used in service provision are not well documented in the literature except that Canada places stress on working within the social determinants of a woman's health, as described in Sheway. Canadians reported a need for client-centred and non-judgmental approaches which acknowledge women's personal experiences and facilitate a sense of safety for any woman who discusses her alcohol use and other life issues. A Canadian service provider claimed future prevention would need to identify alternatives to the current adversarial approach of challenging mothers to address their alcohol dependency if they were to avoid child apprehension or were to have their children returned to their care. This kind of approach is still apparently common.

Interview participants from all countries mentioned the problematic manner in which services for individuals and families living with FASD are delivered. For those living in the United States, this began with agencies not adopting practices that accommodated FASD; some respondents suggested this was linked with prejudice, stereotyping and judgment. For Canadians, inconsistencies were identified across support service systems for women, children and families. The lack of training on the complexity of substance use and intergenerational trauma on families, the lack of shared resources between child welfare and substance use programs, and the lack of collaborative case management were all identified as impediments to progress on FASD.

One of the major obstacles that occurred as a consequence of prevention efforts was 'to construct FAS in the public (and political) imagination as a *children's* health issue' as an outcome of 'maternal ignorance and/or malfeasance' (Clarren, Salmon & Jonsson 2011, p. 17). This translated into prevention paradigms like: (i) protecting children's health by ensuring mothers received the message that their alcohol use was harming their babies, and (ii) redressing health problems through promoting contact with medical or health providers. Service delivery in North America was said not to recognise the needs of the mother and the child, and prevention was strongly believed to be needing a didactic approach to avoid creating a tension between children and women's health. The result was that parents struggled with bureaucrats to access services. This issue was not mentioned in Australian responses.

Services for pregnant women could be improved through more adaptations of mentoring programs like the Parent-Child Assistance Program which began in Washington States and has been replicated in many sites in the United States and Canada. The P-CAP program could be rolled out in other countries and in local regions. For Canadians, the public health message should advise that alcohol in pregnancy is a risk, not a certainty, and should support women to consider choice not just in pregnancy but over their lifetime. In the United States, women's rights need to be protected with equity in alcohol and other drug treatment. However, history reveals the underlying theme of maternal abstinence as the best prevention; this not only devalues the female lived experience but further burdens many mothers and

reduces opportunities for safe disclosure of alcohol use in pregnancy. One of the consequences of increasing public awareness of a problem, when changing behaviour is proposed as a key strategy, is that those who feel blamed are reluctant to seek help for fear of condemnation, whether this fear is perceived or real.

A snapshot of service delivery in the 1990s in the United States reveals state-based perinatal projects to support recovery for pregnant women. Examples include the Early Start project, which began in California and is now a nationally recognised early intervention and treatment program for substance-using women, one that reflects a holistic approach to women's health care; and Project Choices, a national project investigating the impact of motivational interviewing as an intervention technique, increasing the use of contraception and screening women who present with mental health issues and/or physical injuries. Most of these programs continue to operate. In Canada by the 1990s, traditional notions of mothering and the implicit classification of women as a sub-population group were under challenge. Stress as a predictor of maternal alcohol use, together with socio-economic status, employment status, and education attainment, were proposed as the real barriers to managing alcohol use in pregnancy and yet, it was argued that these factors were largely ignored. The efficacy of therapeutic approaches which had failed to respect women's social position in relation to men was challenged. These practices have yet to be embraced in Australia, although the new National FASD Plan endorses the use of funds to prioritise alcohol and other drug treatment for pregnant women.

The inconsistencies in the approaches used to interview women were a concern linked with screening instruments, which can be intimidating. For women who never intentionally used alcohol to harm their children, the consequences stigmatised them and minimised any tendency to self-report alcohol use. It is also likely that women who were asked about their use of alcohol and other drugs were not informed of the teratogenic properties of alcohol. The number of females experiencing harm in the short term is increasing and yet, in prevention policy, girls' and women's health and wellbeing, in respect to drinking, seems to be consistently connected to their capacity to bear children. This position is about much more than the use of alcohol; it is a power discourse, a discourse about gender constructs and about good and bad mothering. It is pervasive, persuasive, and fundamental to contemporary government prevention policy.

Some participants commented on the pervasive impact of alcohol in Aboriginal communities, attributing this to the effects of trauma and fear; the influence of the personal experience of alcohol in the lives of Aboriginal people was not accommodated. There are unanswered questions in how this applies to work practice, given that interview participants who were birth mothers remarked on the importance of open conversations and consistent messages on the risk of alcohol use in pregnancy.

Denial of FASD and the needs of children, women and families seeps through in the lack of effective interventions across disciplines and systems, and exacerbates rather than addresses the problem. For example, the US Surgeon General's statement set a standard based on scientific evidence that was countered in the popular media. Paradoxically, certain voices continue to dismiss the science; yet policy is informed by science. Solutions are handed over to sources of authoritative power and reliant on the acquiescence of those directly affected by the problem – the individuals and their families who live with it daily.

9.5. MEDICAL/HEALTH, DIAGNOSIS AND RESEARCH

FASD is cast as a health condition in all three countries, and all three governments have assigned authority to the medical profession and researchers from the health sciences. Despite this singular approach, diagnosis lacks global consensus and the neurodevelopmental part of the spectrum is considered problematic. By 2001 national health policies in Australia were referencing alcohol use in pregnancy and associated congenital abnormalities, but not FASD: at odds with alcohol and other drug policy frameworks being used in the United States.

The first interdisciplinary clinic was established at the University of Washington in the early 1980s, and many Australians have completed training at the facility. While many clinics offering FASD assessment and supports have been established in the United States and Canada, only two interdisciplinary clinics exist in Australia. Three medical practitioners participated in interviews for this current investigation, two from the United States and one from Australia. In considering the persons or entities whose support would be vital to future prevention, medical professionals from the United States proposed the alcohol industry, any willing entities, tribal readiness and university based research as essential. Future FASD prevention policy would need to focus on ongoing research in the areas of epigenetics, therapeutics and identifying biomarkers to better diagnose those at risk for an alcohol-exposed pregnancy. High level collaboration by representatives from major institutions inside the United States government recognises prevention efforts benefit from a 'roundtable approach' and we need to know 'what will make a difference' (MD0107).

Although one health professional claimed it was necessary to acknowledge that messages about risk do not work, other participants noted the provision of accurate information in medical settings and powerful messages about risk as crucial for future prevention. Future medical practice is proposed to include improved screening and referral for women who use alcohol, and preparedness to provide clinical support to an escalating number of individuals and their parents. Heavy reliance on the medical profession as the technical authority, and the need to persuade policymakers and public alike to deliver prevention messages and diagnose and manage FASD cause a dilemma. In reality, the level of understanding of the condition, and diagnostic capability and capacity are limited. Misdiagnosis is

likely, and it is not expected that this will change in Australia in the near future. Most significantly, the management of individuals living with FASD has become the burden of the parents and families that support them.

Participants persistently raised problems with diagnosis as a challenge to addressing FASD in Australia, with the medical profession unable to accept that the problem exists and that they know little about it. Nor does there appear to be any consensus in the United States on how FASD is diagnosed outside of FAS; and this translates into a subjective interpretation of neurocognitive presentations as misdiagnosis. Early scientific evidence at the University of Washington in the 1970s revealed lower intelligence among half of the children exposed to alcohol *in utero*, and the absence of typical FAE facial features in many cases posed questions about the impact of moderate patterns of maternal drinking. The achievement of 'normal' intelligence scores meant disqualification for disability support; and a lack of significant facial features explains why many adolescents went undiagnosed. According to feedback from participants, new diagnostic criteria are needed in the United States to move towards diagnostic consensus, presenting FASD as a cogent medical condition and a neurodevelopmental disorder.

There is confusion in Australia about diagnostic criteria in the absence of biomarkers, and some cynicism among medical and health personnel as to the significance of the FASD problem. For some participants, the medical profession denounces any information provided by parents and this keeps FASD an 'invisible' disability. It also makes advocacy for those living with FASD extremely difficult, and limits the capacity to demonstrate prevalence rates. Rather than calling the medical attitude denial, one Australian offered research results to explain that health professionals often do not know how to diagnose or are uncertain as to how the problem should be managed. Treatment options are limited and there is a belief that the FASD label will have stigmatising consequences for the individual and parents.

The reliance on the medical profession and health professionals to deliver clinical services to those living with FASD is a double-edged sword. Alcohol and pregnancy are cast as health issues, yet interviews reveal concern about inconsistencies in messages about risk. There is a continual and escalating demand for specialists able to make a diagnosis but only a small number of paediatricians in private practice and two 'on site' interdisciplinary clinics in Sydney and the Gold Coast are available. Without formal training, medical practitioners may avoid making this diagnosis, perhaps lacking confidence in the controversial diagnostic criteria, or the documented inability to create interdisciplinary models of assessment to deliver accuracy in assessment, or because of discomfort in discussing cause with the parents of those referred for diagnosis. These factors remain a very real concern for the future in all three countries. As Conkin (2005, p. 15) suggests, 'the social complexity

of a wicked problem means solutions are a fundamental outcome of a social process' and 'a few brilliant people or the latest project management technology is no longer sufficient'.

The history of FASD began in the United States with research published fairly rapidly and focused on determining a level of high-risk maternal drinking from which to design interventions, and validating the link between the teratogenic toxicity of alcohol and disruptions to otherwise healthy fetal development. Maternal alcoholism captured the attention of scientists at the University of Washington as the common denominator, a focus which has dominated diagnosis to this day.

Prevalence data is considered convincing evidence to support policy, inclusive of funding for services, but is dependent on recognition of who is at risk – women using alcohol in pregnancy and individuals who are affected by fetal alcohol. The urgency to quantify the amount of alcohol that might safely be consumed during pregnancy has currency. However, by the mid-1990s recommendations concerning prevention as inseparable from the complex social, physical and economic determinants influencing alcohol use began to emerge in Canadian government reports. The need for public education, warning labels and intersectoral approaches became major themes despite global knowledge of alcohol as teratogenic and understanding of the determinant factors underpinning alcohol use in pregnancy. The prevention of the problem in Australia continues to be limited to FAS, an adverse fetal outcome associated with high-risk alcohol use particularly in the first trimester of pregnancy.

For the Australians interviewed, there are challenges in FASD not being officially recognised as a disability and in the dependence on intelligence as a measurement of FASD although it is not a reliable measure of the complete spectrum of disorders. Services have not incorporated FASD in their practices, and interested workers have had to individually source information and create their own resources; there is also a tendency for individual client work to be reactive rather than proactive. Poor communication across service delivery sectors has led to duplication in information and resources and, in some cases, competitiveness over the optimal way to offer prevention and intervention activities. In Canada, this is reported as an 'us versus them' approach when as many solutions as possible are desirable; and in the United States, the lack of collaboration allows none of those involved to account for all facets of the problem.

As FASD was cast as a medical condition from the outset, it is not surprising that the role of the medical profession in FASD evoked a strong reaction from interviews. There is a reliance on medical technical authority to change drinking attitudes and bring about behavioural change; to risk-screen and educate girls and women, to build the evidence base, and to identify, assess, diagnose, treat and manage the growing number of individuals and communities at risk. Unfortunately, the interview data suggest this authority lacks the necessary skills and understanding of women who use alcohol or those living with the FASD condition. Maintaining FASD within the health domain and directing the

majority of funding to research within this sphere aims to address the prevention of future children born with FASD. The stories from all three countries and the interview data suggest this approach is not working.

The authoritative voice of medical and research elites holding influence inside government circles and guiding policy decisions is similar in all three countries. It is linked to the status afforded to those with medical expertise; but frequent comments by interview participants indicated the elites offered unreliable diagnoses or misdiagnoses, did not know how to diagnose, feared stigmatising parents, or showed a lack of awareness of the full spectrum of fetal alcohol conditions. Diagnoses were described as limited to the insult of alcohol on normal fetal development; yet in attempts to deal with FASD diagnosis is given the heaviest weight. Moreover, for those living with FASD, in spite of a diagnosis or not, the problem across the lifespan can also be identified as a social problem.

The influence of scientific and medical knowledge had been instrumental for Canada in translating the clinical knowledge base, in the establishment of clinical services and designing Canada-specific diagnostic criteria, and in partnering in research. For Australia 20 years of accumulated knowledge has been accessible from the United States and Canada. The teratology of alcohol was known by the medical profession in Australia by at least the late 1970s, but potential medical spokespersons were relatively silent: only four early research papers were published, and 34 children diagnosed; and research on animal models had begun.

Health-based research to determine risk of alcohol use in pregnancy, rates of prevalence, and government funded programs delivered in the United States since the mid-1990s have been replicated in Canada and are the current focus in Australia. There are at least two consequences of this: first, the principle understanding of teratology that any pregnancy can be vulnerable to the consumption of any amount of alcohol has not been accommodated. Almost fifty per cent of pregnancies are unplanned; and given the rates of alcohol use across all populations, this remains a primary concern. Secondly, high-risk maternal alcohol use in already marginalised communities is attributable to complex phenomena – stress, poverty, limited access to services, personal and cultural shame – and are social constructs, products of social status and not of motherhood, although the personal histories of alcohol use in pregnancy have at times resulted in questioning the legal responsibility of mothers (Australian Medical Association 2014).

Just as public health policy on FASD pays particular attention to First Nation populations in North America, there is evidence in the archival records documented in Chapters 5, 6 and 7 that this pattern has been and is currently replicated in Australia. For example, the National FASD Action Plan (Australian Government 2014) identifies in Point 4 the implementation of targeted measures ‘supporting prevention and management of FASD within Indigenous communities and families in

areas of social disadvantage'. The following strategy under Point 5: National coordination, research and workforce support (p. 3) follows this same theme:

Continue to build the evidence base and improve links between research, policy and practice where appropriate, including promoting the results of the NHMRC targeted call for research on FASD in Indigenous communities.

Financial investment in FAS research ramped up in the United States in the 1980s with government investment through national health research institutions. Prevention pilot projects began in Washington State, and a follow-up study on affected children estimated to be as high as 25 per cent on reservations, was rolled out in First Nation American communities. Accompanying this was a call for immediate government intervention with First Nation populations. The Canadian story is one of rapid acceptance, at least in policy rhetoric, that FASD prevention is inseparable from the complex social, physical and economic circumstances influencing alcohol use; and that gender matters.

Meanwhile, the reliance on evidence-based research and the focus on easy to access population groups have continued unabated. In all three countries, researchers from health academia and professions have engaged in the quest for knowledge variously, approaching from the perspectives of pure science, clinical based studies, epidemiology, genetics or animal models. In its infancy, FASD research revealed the impact of fetal alcohol exposure on neuron migration in the developing fetal brain, evidence that teratogenic risk is not restricted to alcohol 'dependent' women but is non-discriminating. This finding has not had the expected impact on policy. Knowledge of the impact of secondary disabilities or conditions is reflected in education and training but has not assimilated into practice.

Researchers in all three countries have continued to hold leadership and elite positions on national collaborations of varied stakeholders, as authors of key documents, and as advisors to governments. Researchers work collaboratively to determine all manner of Australian-specific evidence and often replicate studies to deliver evidence that reflects the Australian context. The quest for new knowledge on fetal alcohol exposure-related research in all three countries has been selective and has targeted certain population groups, in particular, Indigenous populations of women considered to be at 'highest risk' for an alcohol-exposed pregnancy. At the same time, research has revealed that perhaps half of all women in Australia of childbearing age may be at risk for an alcohol-exposed pregnancy.

If FASD cases are not actively sought, then the majority of them will not be identified, especially those with PFAS and ARND who blend into the general populations because their dysmorphology is not classical, and/or their behaviour is less dramatically affected (May 2011, p. 23).

Research is necessary to address the effects of alcohol on the unborn, identify best practice treatment services, offer prevention, implement longitudinal studies and identify potential biomarkers indicative of FASD risk. In addition, the effects of cortisol/stress on fetal development when women are living with stress and anxiety are an important new area of knowledge needing to be acquired for the future. However, discretionary targeted research and prevention activities have meant that most individuals living with FASD remain ‘invisible’ although the activities satisfy governments caught between managing the health of the nation and handling the powerful influence of the alcohol industry. The essence of the problem, the cause for concern, is mobilised and perpetuated as certain women in certain communities and the true problem – alcohol – is denied.

Researchers from the United States who were interviewed generally agreed that prevention efforts need to target all women at risk, and not just those who are easily accessible, and to focus on clinics where women are going, providing more front line interventions and improved support for providers. The use of more subtle messages to promote women’s consideration of their choices is probably less confronting and creates safer environments for pregnant mothers, encouraging good health before pregnancy as a proactive choice.

In Canada, a personal response approach with less shame and blame is proposed; for Australian researchers who were interviewed, regular intervention prior to pregnancy using brief interventions in obstetrics and antenatal care, coupled with a sustained screening and diagnostic instrument and minimum data sets for reporting and recording alcohol use, are needed. A researcher from the United States concurred with screening all women of childbearing age, and added the need for improved and expanded surveillance in screening both women and ‘screening for FASD’ as important in the future. An Australia researcher believed there needs to be acceptance that we will not prevent all FASD.

9.6. STAKEHOLDER REPRESENTATION

Successful collaboration has the purpose of engagement rather than alienation. The belief that service providers and funders will be forced to confront the problem of FASD with prevention measures is contrary to opinions expressed in all three countries. While those people interviewed cannot be claimed to represent all views, there is, even within this small number, a striking difference in opinions even when there are similar backgrounds or life experiences. This is consistent with Rittel and Webber’s wicked problem theory: that stakeholders realistically opt for the explanations which are ‘most plausible’ and which represent their ‘world view’ (Rittel & Webber 1973, pp. 166, 169; Roberts 2000, p. 5).

Parents from all countries who were interviewed said that their interest in the FASD problem came from their care of children and the personal research they had had to undertake to access information.

Service providers described their interest differently, as motivated by FASD educators and trainers or the presentation of multiple cases in their client caseloads or community.

Interview participants reported early interest in the problem in the United States as coming not from the grassroots community but from scientists who were able to articulate the technical details of the problem to a broad audience base, from scientific evidence or the work of small groups of public servants (NIAAA), from politicians and from advocacy groups (National Organization for Fetal Alcohol Syndrome; FASWorld). By 1996 in the United States, the Interagency Coordinating Committee on FASD had been formed: a collaboration of government health services. By the end of the decade a national taskforce had been created by the Center of Disease Control with formal community representation by NOFAS and SAMHSA which had launched a FASD Center of Excellence. While some interview participants named individuals, more often the CDC, NIAAA and SAMHSA together with the Indian Health Service (HIS) and the Health Resources Services Administration (HRSA) were identified as important sources of influence on the problem of fetal alcohol exposure.

For Canadian interview participants, the influence of scientific evidence was not mentioned apart from the western provinces' geographical proximity to the University of Washington and some information exchange that informed early parent advocacy. In the absence of Canadian information or resources, proponent groups emerged, the most influential a collaboration of parents, some service providers, bureaucrats and a few politicians in British Columbia in the 1980s. The BC FAS Resource Centre (founded in 1985) and the FASN listserv (established in 1991) were mentioned by Canadian participants as responses to the absence of specific resources on FASD and the work of parents to address this issue. By 1992 an FASD Strategic Plan was in place in British Columbia, dealing with difficulties in coordination and collaboration, implementation and meeting longer-term goals. Little connection between groups was noted; nor was any significant impact on governments and/or social agencies to move the fetal alcohol exposure and FASD agenda forward. Overcoming community denial of the problem was identified at the time as a future challenge.

At national level, the Canadian federal government engaged in policy-making on FASD through Health Canada by 1992, a process inclusive of Aboriginal community representation. Health Canada published 'FAS: The Preventable Tragedy' in 1994, a health promotion framework recognising complex social, physical and economic impacts that required an intersectoral approach. By 1996 a Health Canada Joint Statement on FASD with 17 co-signatory organisations indicated that national collaboration would be assured, with recommendations for greater attention to treatment programs for women using alcohol.

An important collaboration emerged in 1998 when the Prairie Province FAS Partnership formed, and by the following year six provinces and territories had membership. By 2003 seven jurisdictions had partnered and the name was changed to the Canada Northwest FASD Partnership. While this is a partnership of provincial and territorial governments, collaborations in the United States reflect membership of a range of stakeholders outside government. Australian forums and committees have tended to be dominated by researchers and academics, medical professionals and senior bureaucrats, with a few representatives from the non-government sector, and parents.

The United States does not have a national FASD strategy, and so was not mentioned by United States participants. Scientific research initially attracted attention to the problem of alcohol use in pregnancy, and the US Secretary of Health & Human Services and the US Surgeon General, together with champions in Congress, emerged from interviews as sources of significant influence. FASD is managed at a federal level through key national health institutions that function on behalf of the federal government – public health, infant and child health, and Indian health. These organisations were named by United States interview participants as crucial to funding continuing research and prevention initiatives. It is in this high-level policy context that the IGC-FASD, for example, is situated. The Federal government of Canada had a national FASD plan in place by 2001, evolving from best practice research and consultation through stakeholder forums, and was updated in 2012. Archival records and interviewee responses suggested that Canada has always consulted more widely than occurs in the United States or Australia. The provincial governments of British Columbia and Alberta have developed their own FASD action plans, complemented by multiple partnerships across portfolio areas and cross sectors, and based on the early understanding that FASD prevention did not fall within a single policy stream. Interestingly, while there is reference to the collaboration involved in the drafting of these documents, there was no comment in the interview data about advancing the strategy in the future.

The importance of advocacy and cross-sector collaboration in advancing FASD prevention policy is evident from comments made in many of the interviews, regardless of country or interest area. There was agreement across all three countries that governments impede progress. For those from the United States, government controls, allocated program funding and insufficient resources invested in prevention and intervention were negatives. There was unspoken denial of the actual numbers of individuals living with FASD and the need these people had for special education and other services. This translated as a financial burden and additional stress for families. Likewise, Canadians complained of lack of funding for FASD programs and the insufficient evidence of incidence or prevalence rates to mobilise attention. For Australians, there was no communication across government jurisdictions and a general reluctance of policymakers to engage with the issue, often masking the impact of alcohol by drawing greater attention to illicit drug use as a policy priority. In

one participant's experience, reluctance may express hope that a problem will disappear and those living with the problem will be accommodated by current service delivery options. This participant also pointed out that reluctance might be connected with not wanting another major issue to deal with. Even with progress concerning FASD over more recent times, some Australians agreed there was a lack of political will to deal with the problem: limiting approaches to research satisfied the government that the problem was being managed.

Dorris (1989) wrote of the human story, the tragic consequences of life for an individual living with FAS in the United States and the impact on the adoptive family. The author's television appearances to promote FASD and his book sparked public attention to the issue and, according to US participants, triggered public awareness of FASD and led to the establishment of community-based support organisations. In Canada, advocacy began with the formation of parent-led organisations like Faslink and Fasworld; in Australia, advocacy came from NOFASD Australia and, later, the Russell Family Fetal Alcohol Disorders Association (RFFADA).²⁵

From the 1980s the sharing of information across the globe was expedited by the burgeoning World Wide Web; and whatever their role, this connection brought together people who shared a common interest in the prevention of FASD. *Iceberg*, for example, was published online from 1991: a newsletter of scientific research on the fetal alcohol problem, it was the product of a parent–professional partnership through the University of Washington. Australian advocates benefited too from online contacts, reference materials and resources accessible via the internet. Contact with experts led to attendance and training opportunities at the University of Washington and the Asante Centre in Canada, and this knowledge translated into the application of an interdisciplinary approach to assessment and diagnosis. Canadian international FASD conference events held annually since the 1990s have provided more useful network opportunities.

Advocacy in Canada and Australia built on shared knowledge moving across borders to be picked up by parent/carer mobilised groups. A report by the Canadian Centre for Substance Abuse in 1999 revealed that over half of those involved in the FASD problem arena were in local coalitions or committees in the western provinces. As had been the case in Canada with the formation of the BC Resource Society or FASN listserv, in Australia parents' reaction to limited resources and the poor interest of government in the prevention of the problem led to the establishment of the non-

²⁵ More information on Russell Family Fetal Alcohol and Disorders Association (rffada) can be accessed online: http://rffada.org/images/stories/documents/rffada_History.pdf

government entity NOFASD in 1999. Miers travelled to Canada and returned laden with information, and yet despite reports from Canadian conferences, NOFASD Australia could not attract the committed attention of government. Miers connected with a few medical professionals and researchers who were interested in the issue, including Dr Carol Bower and Dr Elizabeth Elliott from the Australian Paediatric Surveillance Unit and Professor Eric Haan, a geneticist from South Australia. Collaboration with multiple stakeholders outside the scientific research area and a few selected lay participants are not indicated in the archival records. The first formal collaboration did not occur until the formation of the Australian FASD Consortium to facilitate development of the diagnostic tool.

The responses to leadership in advancing FASD policy resulted in a diverse range of opinions, which were at odds with the events relating to collaboration. For United States participants, there was little national leadership on the issue and a generally shared perception of a lack of coordination among FASD stakeholders who were willing and trained to advocate consistently for a coherent and concise set of recommendations. There was one claim that FASD had not reached the critical mass necessary to influence policy-making effectively. Reasons for this were linked to: (i) children and adults living with FASD who had been either undiagnosed or misdiagnosed; (ii) parents and families focused on meeting their own needs, making national advocacy difficult; (iii) the stigmatisation of the birth mother and FASD sufferer; and (iv) the need for stronger incentive-based leadership from NOFAS and other organisations. These ideas are similar to the understandings shared by both Canadian and Australian participants, and seem to have persisted over time.

When a problem is symptomatic of a much bigger problem, or there is a lack of agreement on the problem's definition and solutions; and when decision-making that does not work has consequences, the stakeholders and their unique 'world views' need greater consideration. This is described as 'the strongest determining factor in explaining a discrepancy and, therefore, in resolving a wicked problem' (Rittel & Webber 1973, p. 166). The original demands for public awareness and appropriately informed service delivery were easily overshadowed by scientifically quantifiable and therefore more authoritative strategies. Most notably in the Australian context, this reinforced the fundamental research bias by targeting some women and some mothers through research. It failed to address alcohol use at the whole of population level.

9.7. FASD AND PUBLIC POLICY AGENDA BUILDING

Fetal exposure to alcohol as the cause of FASD is not disputed, but it does mean that FASD is part of a much bigger problem system: the harms caused by alcohol. Differences of opinion *are* noted when it comes to addressing responsibility. The alcohol industry is not sufficiently accountable for its products and is highly influential inside government circles

to protect its commercial interests, leading to a common criticism among public health professionals that the industry has been influential in setting the policy agenda, shaping the perspectives of legislators on policy issues, and pushing alcohol policy towards 'self-regulation'. (Doran et al. 2010, pp. 468–470)

For those who recognise the fetus as a living entity, mothers who drink at high-risk levels and particularly women who could, but choose not to, abstain are the problem. Regardless of position, FASD is an outcome of a social problem which requires change in attitudes to drinking and behaviour.

Any increasing conflict over problem definition or solutions was curtailed with the introduction of authoritative-type strategies. For example, warnings on alcohol beverage packaging had been introduced in the United States by 1977 and control over prevention and research was devolved by Congress to the NIAAA and other national health research institutions. In Canada, the Federal government acted quickly to consult and publish a framework for action in 2003 (Public Health Agency of Canada 2005). The document offers guidance to provinces, territories and local communities on managing the problem. The provincial governments of British Columbia and Alberta were the first provinces to have government support for FASD public policy and over recent times, public policy interest is rolling out across other provinces and territories. In the current research, some participants argued that prevention happens best in the local community; however, it must be said that research trends in two directions. First, it is collaborative and essentially the work of women from diverse backgrounds. Second, it continues to dominate in First Nation communities. In Australia, policy-makers embarked on an evidence based policy approach intercepted with some community based research in marginalised and Aboriginal communities with *ad hoc* investment in national forums.

Whether the public policy is to invest in research or to target only marginalised communities or some women drinkers, there are consequences to such discretionary approaches. Government investment in preferred solutions means the universal prevention message is not in place and efforts are concentrated on children and those living with the problem, particularly those older children and adults who are undiagnosed, misdiagnosed or unrecognised and do not have a voice. The overall influence of leadership is in some doubt because of the power of the alcohol lobby and the socio-economic climate in all three countries which favours alcohol. Alcohol is a highly profitable commodity and a cultural norm, and there was little doubt in the minds of many of those interviewed that the issue of FASD has been suppressed by the alcohol beverage industry.

Interview data reveals a greater need for governments to be involved in the solution, but challenges to this approach are evident. First, governments must manage any public opposition to the repositioning of alcohol in society as this could cost votes. Second, governments must balance the powerful interests

of the alcohol industry and its own stake in revenue derived from the product. Third, this must be achieved against a moral, ethical and even perhaps legal obligation to alert the public to a major public health issue, which will be a fraught situation. Differences also occur in prioritising public funding for FASD and where it is best invested.

The influence of national institutions has sustained FASD as a health issue and translated into policy that favours solutions focusing on researching clinical intervention and service delivery models and finding innovative ways to prevent alcohol use among women of childbearing age. A sharpened focus on alcohol, pregnancy and infant health, which gained momentum in the late 1970s in the United States, has continued, with surveys to collect data on women's use of alcohol during pregnancy, and research aimed to elucidate the personal characteristics and life experiences of high-risk drinking women. These inform prevention efforts such as Project Choices. Online manuals with content linking healthy pregnancy with healthy babies are repeated across three decades of FASD.

Over time the problem for governments has been contained and the original proponents' demands have been suppressed. Governmental management of the problem has been guided by medical professionals, researchers and academics with privileged position who are 'closer knit in background, mores and goals' (Cobb, Ross & Ross 1976, p. 135). There are reciprocal benefits of status and funding investment.

Given the complexity of the problem and the reliance on changes to belief and culture as the most likely solution, the stories and comments from interviews reveal the diversity of opinion about barriers to prevention and what needs to happen in the future, even among those who share similar backgrounds and stakes in the problem. The role and influence of governments; of medicine and medical professionals dovetailing with both diagnosis and influencing the investment in research; and the contribution of parents and carers in ensuring support and services for those who have no voice, aid in teasing out how best to manage this problem in the future. For the individuals living with FASD, the optimal future is consistency in diagnosis. Screening, assessment and diagnosis have been the focus of work in both the United States and Australia. The link between accurate diagnosis and capturing data to estimate prevalence, and the ability to convince policy-makers of the seriousness of the problem, has been well noted. The development of diagnostic tools in all three countries has not led to uniform standards, which adds to the conundrum surrounding the neurodevelopmental part of the spectrum in identifying those individuals recognised at risk for FASD but not presenting the characteristic features associated with FAS.

Since 2002, the story of Australian government investment in FASD prevention has been marked by an ebb and flow approach. National forums sponsored by Federal government in 2003 and a government funded literature review showed promise. Guidance at a national level had been initially

managed through government created institutions like the Australian National Council on Drugs and the National Expert Advisory Committee on Alcohol within the National Drug Strategic Framework. A second National Fetal Alcohol Syndrome Workshop in 2009 and the FASD Monograph in 2012 was followed by a Commonwealth FASD Action Plan launched by the then Labor government following extensive, but hasty, consultation with stakeholder representatives in 2012. Research, diagnostic tool implementation and National FASD Technical Network as the government's advisory group were established together with funding allocated to alcohol and other drug services to prioritise treatment for women with substance use issues in pregnancy and improving education on FASD among Aboriginal mothers.

9.8. FASD AND FRAGMENTED PROBLEM MANAGEMENT

In applying the ten characteristics of wicked problems, the archival records and interview data provide evidence that FASD is a complex and intractable problem, and that despite attempts to address the problem, little headway has been made. There is no definitive formulation of the problem: information on FASD is vast and yet incomplete, with many questions unresolved. In this research the diversity of responses in the interview data and the scope of key events in the stories of FASD in three countries is open-ended, and this says much about the problem context, endorsed by the claim by Rittel and Webber (1973, p. 161) that the 'formulation of a wicked problem *is* the problem!' If the problem is the absence of a definitive formulation, then the conclusion follows that possible solutions cannot be described or tested and will have unexpected consequences.

The shift in pattern is demonstrated in Figure 2 below, an adaptation of Roberts' (2000, p. 3) 'Coping Strategies to Deal with Wicked Problems'. Depending on which expansion strategies are used by originator groups in the initiation stage, different groups enter the problem system. Each has a different frame of reference which determines their unique and preferred definition of the problem and its possible solutions. The greater the disparity in definitions, the more removed from the initial demands the engagement groups may be. Rather than being understood as a multifaceted problem with many stakeholders representing diverse contexts, the focus of policy shifts, resulting in a fragmented approach.

One of the key challenges to consistently emerge from the research concerns the diagnosis of the problem. There is convincing data to support the notion that the measurable part of the spectrum of fetal alcohol harms – Fetal Alcohol Syndrome – is given priority over other aspects of the condition. A manifest consequence is the inequity experienced by those directly affected by FASD and their families. While the initiators have made demands for public policy attention to FASD prevention and services for those living with the problem, current approaches still favour medical models to guide government policy. Researchers receive the bulk of government funding, and have used it to focus on

marginalised population groups and communities in all three countries and to manage other stakeholders.

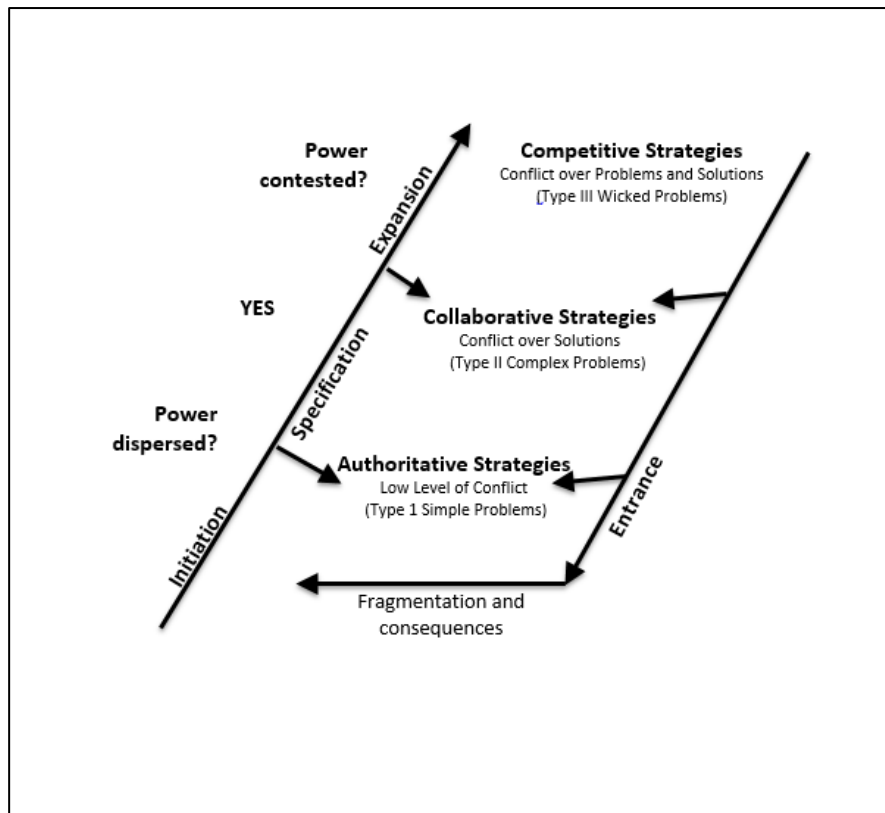


Figure 2 FASD problem system: an amalgamation of network approaches to wicked problems and the stages within patterns of public policy agenda-building

This has led to authoritative solutions and over four decades has resulted in limited success in addressing the problem. For governments, this has served to ensure the problem of FASD appears on formal policy agendas in the United States, Canada and Australia, and a shift from an ‘outside’ government to and an ‘inside’ government-initiated pattern of public policy agenda building which has suppressed the problem from the public agenda. Adapted from Figure 1, Figure 2 below presents FASD as a wicked problem, visualised as moving through the four phases of public policy agenda building: initiation, specification, expansion and entrance.

The presence of multiple stakeholders with diverse frames of reference, even within the same attention groups, means that controlling the level of conflict in dealing with FASD is central to issue management for governments. Conflict has, and will, increase exponentially as more stakeholders engage, but may counter problem fragmentation; the invocation of authoritative strategies follows. Roberts (2000) identified problems as simple, complex and wicked; each is defined by a corresponding level of conflict. This is what Figure 1 shows. The wicked problem is perceived as a

simple problem and by the policy entrance phase is managed with authoritative strategies, proposed in this research to be best suited to the government policy approach: the continued search for scientific and evidence based policy, a problem best guided by medical ‘experts’, and responsibility placed on the individual drinker.

The problem of FASD is, in all three countries, contained within a health paradigm which by default is subject to scientific rigour. Unlike other health issues – autism for example – fault is attributed. While autism has a spectrum of conditions and is dependent on clinical diagnosis, it does not target mothers as the source of prevention; nor is it attributed to use of a commodity like alcohol. The incidence of autism is not greater in particular population groups. To recognise FASD as a similar social issue is a conundrum for governments, as policy-making would then require considering FASD in the context of bigger problems like the culture of alcohol use; and commercial and economic interests would further add to the problem’s complexity. The fracturing of the FASD problem into various parts is a consequence of the zealous reliance on empirical evidence as fundamental to locating a prevention solution, even if in the meantime the impact for individuals living with unrecognised FASD and the burden on parents and families is tragic and ignored.

When a fragmented problem is understood to represent multiple frames of reference, the interests of disparate power bases create a breakdown of the issue into parts which may have single solutions and are manageable as ‘rational–technical approaches’ (Head & Alford 2008). As Roberts (2000, pp. 14–15) remarks, it ‘seems more productive to be mindful of “taming” wicked problems by a handover to experts or power base for definition and solutions’. If no one is in ‘control ... then it is unlikely that the experts and leaders will be able to act unilaterally to define the problems and their solutions’:

The power of those who can articulate and mobilise their preferred definition and solutions has meant a focus on a simple problem model described as a ‘Type 1’ problem (Roberts 2000, p. 1).

Such simple problem solutions assume ‘consensus’ in both problem definition and solution, and a reliance on authoritative types of coping strategies, a reliance on ‘more professional and specialized experts who are assumed to have relevant skills limited in the general public’ (Roberts 2000, p. 1). The consequences are restrictive ‘options for resolution within the narrow scope of professional expertise’, limited opportunities for ‘important issues and considerations’ to be contemplated, and ‘lost opportunity for learning’ (p. 5). Quantitative approaches to prevention as authoritative solutions are measurable and add to the evidence base. Such approaches obscure the need of families struggling to support those living with the condition in the absence of support services.

9.9. SUMMARY

This analysis first attends to the importance of advocacy, leadership and collaboration in bringing the problem of FASD to the attention of policymakers and maintaining policy interest. Differences appear in the informal or formal structure of collaborations and the manner in which respective polities respond. In the United States the problem was first raised in the health science research arena and now falls within the domain of national health institutions which are mandated to report on progress to Congress. Canada differed on two fronts. The collaborative effort came from an amalgamation of diverse representatives who worked with parents, and from the outset strategies acknowledged the challenges ahead and determined that change would happen at a local level with guidance. Key authorities included those who promoted gender as a central feature in prevention planning. In Australia, initial proponents were parents, and little traction was gained until researchers and academics entered the arena.

The interview data reveal a trend towards reliance on the medical profession, recognising consistency in assessment criteria and diagnosis as the key to greater awareness in the future and in securing better outcomes for those living with FASD. What is also revealed in the stories and interviews is government reliance on the technical authority of key medical professionals and on evidence-based research. There was criticism from interviewees of the failure of the medical profession to inform and educate, to diagnose, facilitate and augment individual case management, and to collect data and participate in research.

While the current pattern is retained, stakeholder needs are compromised. This is not so much of an issue for those in the United States. While American interview participants spoke of defining the ‘D’ in FASD, increased resources and commensurate funding, Canadian focused on better outcomes for population groups: women, children, juvenile and adult corrective services clients and viewed this as attainable with improved collaboration with parents and better service delivery systems. For Australians, demands were dependent on the individual’s stake in the matter, and were often connected with personal experience. Researchers and medical professionals spoke of the need for continued research, birth parents on their often less than favourable encounters with the medical profession. For carers, the pressing issue was improved understanding, with knowledge of how FASD affects cognition, development and needs across the lifespan.

Through the stories and interviewee data, many stakeholder groups were shown at work. Each championed alternative solutions and competed to frame ‘the problem’ in a way that connected to their preferred solution. FASD is about unequal power. As Atwood et al. note, it is more often the case that ‘preventive action seems to lag behind the state of public health science’ (1997, p.1603).

Similarities across the three countries are greater than differences. FASD continues to be framed as a health issue, but when the impact on people's lives is considered across the lifespan, it is equally a social problem. The technical details concerning the development of brain and body structure means the scientific elite has been sanctioned by governments to guide management of the multiple facets of the problem. This denies opportunities to engage with the diverse knowledge bases that could contribute to fuller, improved management of the problem. The harms caused by alcohol are immense and the cost in economic, health and social terms are profound; FASD as a wicked problem is also a political problem. How does a government explain the toxicity of a substance on fetal development and the lifetime implications of FASD to an electorate that loves alcohol? Is this the essence of the FASD problem and its intractability?

There is awareness of the teratogenicity of alcohol and the risk from any alcohol but no definitive definition of the minimal amount that will cause fetal harm. There is advanced knowledge and understanding of how the brain is particularly vulnerable to fetal alcohol exposure and how impairments impact on individuals across the lifespan. There is also sound knowledge that FASD is not just a health system issue in that the individual living with FASD often has complex needs which translate to financial dependency, unemployment, family breakdown and social isolation, homelessness, alcohol and other drugs dependencies, incarceration and mental health problems. Hence, there is acceptance that FASD as a problem crosses multiple systems with high economic and intangible costs. This occurs in social and cultural contexts that not only promote alcohol consumption but are reflected in policy positions which deny the breadth of the problem by marginalising the problem as belonging to discrete population groups – high-risk drinking women, Aboriginal and First Nation communities. Consequently, the stakeholder group is expansive and growing – medical and allied health professionals, clinical and non-clinical researchers, parents (birth, adoptive and foster), justice, non-government and government organisations. FASD prevention (raising public awareness, targeting high populations at risk, and targeted intervention or treatment for those who already live with a condition) separates the girl/woman who is drinking and may be at risk for an unplanned pregnancy, who consumes alcohol in pregnancy, from those who are recognised as at-risk or have a diagnosis of a FASD.

CHAPTER 10 CONCLUSION

Cast as a wicked problem, FASD is characterised by complexity, ambiguity, a lack of agreement on definition and solutions, and resistance to traditional linear solutions. Multiple stakeholders engage in the problem system with diverse frames of reference and preferred definitions of the problem and its solution. The level of contestability, and who dominates, determines the dominant strategy (authoritative, collaborative or competitive). This research aims to better understand the influences on a wicked problem as public policy, and explores attempts at solutions through a comparison of three similar countries. The research makes some proposals about why, in light of scientific evidence, FASD remains an intractable problem, and explores some possible explanations for public policy resistance in Australia. It is proposed that FASD remains an intractable problem despite ‘the transposition of policies and/or practices already in operation in one jurisdiction to another’ (Roberts, 2000). Whichever way the problem of FASD is viewed, value systems and power dynamics come at play. FASD is embedded in conflict and, therefore, is essentially contested.

This research began with an overview of FASD as a case study, followed by separate chapters detailing key events which shaped FASD as public policy issue in the United States, Canada and Australia. A multiple method qualitative approach complemented the stories of FASD with data from stakeholder interviews. This facilitated an exploration of key events and of individual interpretations of the impact of the problem and potential solutions, from multiple perspectives. For some, their role and interest in the problem was medical or research-based. For others, FASD fell within the scope of client service delivery, education or workplace training, and for the reminder, FASD was the condition which they experienced as parents and carers.

A conceptual model of agenda building (Cobb et al. 1976) was used as a framework for understanding the progress of FASD public policy from the original demands of scientists from the University of Washington in the United States, a collaboration of parents, medical professionals and politicians in Canada, and a small grassroots initiator group in Australia. Attracting the attention of public policymakers required expansion strategies to include attention groups, groups who shared the original demands but who also had influence inside government. Medical and research elites with an interest in FASD. For instance, supported the originators of the original grievances but preferred definitions of the problem and solutions. These changed the original dynamics and led to public policy preferences for authoritative solutions.

The handing over of the FASD problem to those with technical authority to guide policy revealed a shift from an outside initiative pattern to an inside initiative pattern of public policy agenda building. In Chapter 3, the outside initiative model was described as occurring when issues or grievances raised

by groups outside government aimed to attract the attention of decision-makers and reach the formal (governmental) agenda, but also to expand sufficiently to raise public awareness on the public agenda. The transition from public to formal agenda was noted to be neither automatic nor speedy. In industrialised countries, the process can be stalled if the subject arouses public opposition and governments refuse to take action. Counter to this pattern, an inside initiative pattern occurs in situations where 'automatic' status on neither the formal nor the public agenda is sought by the initiators.

In the case of FASD, this thesis argues that the initiators are policy-makers inside government or from groups close to political decision-makers. Cobb et al. (1976) note that successful progress of the problem to the public agenda is dependent on a select expansion to certain influential groups for the necessary support, but at the exclusion of the general public. These influential groups offer the least risk of change to the policy proposal and, if the new policy is in their interest, they may use their position to influence government leaders or decision-makers to act as brokers, initiating the new policy' on their behalf so that their interest remains relatively silent (pp. 135, 138). While FASD is on the formal policy agenda, the problem has stalled on the public agenda in Australia. This strategy avoids disputes with the alcohol industry and helps avoid any perceived dissension within the electorate, in this case about the personal choice to use alcohol.

As Conkin (2005) notes, the social complexity of a wicked problem means solutions are a fundamental outcome of a social process and 'a few brilliant people or the latest project management technology is no longer sufficient' (p. 15). The original demands for public awareness and appropriately informed service delivery have been overshadowed by strategies that are scientifically quantifiable and therefore authoritative. As multiple stakeholders have an investment in both definition and solutions of this problem, the prioritisation of some strands of investigation invokes consequences, as predicted in wicked problem theory. Most notably in the Australian context, it has reinforced the fundamental research bias in targeting some women and some mothers through research. It has failed to address alcohol use at a whole of population level.

This research shows that in order to attract the attention of public policy decision makers, initiator groups in each country engaged with people or groups who could better articulate the technical details of the problem and who had the necessary influence inside government. This had certain consequences. The scope of possible 'world views' in the FASD arena expanded exponentially with increasing participation and engagement, and brought increased risk that handing the problem over to a different set of stakeholders would 'demote' the initial demands in favour of that set's preferred position. As problem context and different definitions of the problem become evident across stakeholder groups, a struggle for preferred solutions emerged. Engaged stakeholders with technical

authority and who privileged status remained supportive of the original demands of the initiator groups but represented wider, and sometimes different, interests.

In Figure 2 above (p.172), the phases of specification and expansion within conceptual patterns of public policy agenda building align with the type of problem, becoming more complex and competitive as more diverse groups enter the problem arena, increasing the risk of conflict over problem definition and solutions. The increased level of competition leads to problem classification as Type III or wicked problems. I argue that expansion and increased competition is dominated by those groups that policymakers preferred. As other stakeholder voices are quietened, specification and expansion phases give rise to a shift from an outside to an inside initiated pattern of public policy agenda-building. In the inside initiated pattern expansion is limited to influential groups but not the public, effectively removing the issue from the public agenda. Problem solutions are essentially a private decision reached within government.

Rittel and Webber (1973) propose that wicked problems may never be solved, perhaps because such problems are defined by different stakeholders differently: cause, seriousness, and solutions will be dependent on who is asked. Differences can also create disagreement and conflict which may present through pressure on decision-makers' attempts to tame a wicked problem. It stands to reason that if wicked problems are also socially complex problems and require behavioural change, simple solutions based mainly on the technical details of the problem are unlikely to lead to resolution. Moreover, simple solutions can lead to unforeseen consequences including 'taming' approaches.

Social problems are never solved. At best they are only re-solved – over and over again [for] the process of solving the problem is identical with the process of understanding its nature.
(Rittel & Webber 1973, pp. 160, 162)

Managing the problem with authoritative strategies fails to address the competing demands of stakeholders. Trade-offs between conflicting goals, solutions that will involve coordinated action by government, the involvement of non-government agencies, private business and individuals, and more innovative, personalised approaches may be needed to motivate change. Collaborative strategies are proposed as the best approach when behavioural change is required as part of the solution. As Roberts advises, 'people have to fall into collaboration' (2000, p. 12). This requires a level of confidence in the process, particularly by those who seek to dominate, take control or hand problem-solving to authoritative experts who can tame disputes:

Our diverse interests and perspectives become a curse when each stakeholder believes it holds 'the truth' and expects everyone to share it, or worse, when a stakeholder wants to impose his

view of truth on others and considers anyone who refuses to accept it as dumb, ignorant, or morally deficient (Roberts 2000, p. 13).

The characteristic features of wicked problems give a structure from which to understand the intractable nature of FASD as a problem system. We are reminded that a wicked problem is one with no definitive statement; a problem for which linear methods do not work; a problem that is ambiguous, complex, political and frustrating; a problem which defies solutions. Important to this thesis is the proposal that FASD is a problem system which is covertly competitive and fraught with alternative solutions championed by stakeholder interests promoting preferred solutions and problem definition. In collaborative strategies, arrangements and explanations are less proscriptive, the attendees list is more open and the activities are more likely to accommodate diversity in work environments and organisational relationships and structures. Such focused attention may achieve consensus in devising strategies and planning action in smaller “self-managed” groups, which may prioritise concerns based in the seeking of common ground rather than focus on differences’ (Roberts 2000, p. 11).

The emergence of elite research academics in collaboration with medical professionals with an interest in FASD is not surprising, given their ability to articulate the technical details of a problem and can use their status, connections and published papers to convince policymakers of their preferred position in respect to problem definition and solutions, fracturing the problem into ‘manageable parts’ and obscuring the full FASD problem system. Stakeholder groups with power and influence can move to authoritative strategies which deal with low levels of conflict because the initiating individuals and families who are directly affected but no longer have a voice are assumed to acquiesce. In the application of authoritative strategies, an unforeseen consequence emerges as the preferred fraction of the problem creates its own smaller wicked problem: diagnosis, lowest threshold to cause fetal harm, target groups, interventions. In the entrance phase, a new agenda-building process emerges in the authoritatively defined problem space as government selected, elite participants strengthen the new proponent position, suggesting urgency in terms of policy priority while denying the public the opportunity to bring oppositional pressure (Cobb, Ross & Ross 1976, pp. 126–138). The entrance phase is a government-controlled space, marking the shift from outside-initiated.

As the data and literature suggest, parents and carers or their representative agents have unilaterally struggled for change which would address the ‘invisibility’ of the problem, not just in Australia but globally. Policy and medical audiences are necessary to facilitate a clearer expression of the critical need to raise public awareness, and in imparting an understanding of the characteristic features of FASD as having a physical brain-based aetiology with behavioural symptoms. These critical factors are understood to be commensurate with the implementation of appropriate services in all institutions with which those living with FASD must engage.

Wicked problems are problems with no absolute definition, dealing with ambiguous and complex issues with political implications. They are fraught with alternative solutions preferred by diverse groups of stakeholders. These characteristics provide a plausible understanding of why FASD is such an intractable problem and why, after 40 years, many of the issues advocated for in the late 1990s have not yet been resolved. The technical complexities of FASD are in contrast with the problems in its social dimensions, an important factor to consider when proposing approaches to manage this wicked problem.

As Conkin (2007, p. 9) explains, ‘no linear process will work with a wicked problem’ because the linear ‘design effort must start producing robust solutions just to illuminate the hidden issues and flush out the hidden stakeholders’. Roberts (2000, p. 16) points out that no one entity can be ‘in control’ of a wicked problem: there can be no unilateral decision on what the problem actually is or how to resolve it. FASD is a problem *system*, and this means all parties need to trust in a learning process built on collective equity.

Roberts writes about ‘a willingness to trust the process without guarantees of a particular outcome’ (Roberts 2000, pp. 14–15) and the creation of a ‘community of interest’ which would identify common ground and a focus on areas of joint interest, open to self-organisation and co-evaluation. Australian interviewees reported that collaboration was informal and somehow worked, but that co-ordination was limited. Could such a community of interest be possible in Australia in respect to FASD prevention? It would require collaboration and the accommodation of different views on causation and responsibility for alcohol use in pregnancy, accommodate the needs of individuals and families currently living with FASD and the scientific evidence that is necessary to prove incidence and prevalence in the wider community. Prevention goals are worthy for wider consultation and deserve greater public policy attention. Solutions will involve coordinated action by governments, non-government agencies, private businesses and individuals, particularly if behavioural change is required as part of the solution.

As noted by Head and Alford (2015, pp. 713, 716), the notion of homogeneity has been replaced by social groups with more diverse ‘aspirations, values and perspectives’, and there is a need to accommodate ‘social pluralism, institutional complexity, scientific uncertainty’. There is longstanding scientific evidence of a link between alcohol toxicity and adverse fetal outcomes. FASD has never been merely a public policy issue of a highly technical nature and policymakers continue to deny the consequences for those living with FASD. The problem has both moral and ethical implications, particularly in light of government support of a highly profitable industry that works against the public health, perpetuating an issue of major concern.

There are leaders in Australia who could, in the absence of adequate resources, bring the ‘community of interest’ together and bring ‘a degree of coherence and mindfulness, if not control, on its workings’ (Head & Alford 2007, p. 728). Head and Alford suggest leaders can mobilise ‘adaptive work’ (p. 730), not only by those ‘in senior positions or management roles’ (Australian Public Service Commission, p. 14). When asked about the future, interviewees articulated very diverse opinions, even when from similar backgrounds. Many concluded that the essence of the problem lay at the interface of three elements: (i) reliance on the medical professions for the diagnosis and management of the FASD condition; (ii) resolving the diagnostic criteria to account for the entire fetal alcohol spectrum; and (iii) disbelief of or disinteresting of the scope of the problem by physicians.

Reducing the harms caused by alcohol across the social spectrum has been underpinned by a harm minimisation policy. For those we might call ‘good drinkers’, youthfulness, peer pressure, social life and even claims of better health are factors in policy consideration. For older people or those who have developed a dependency, a disease model is applied and responsibility is set beyond the control of the individual. For others who might be called ‘bad drinkers’, alcoholism is constructed as a social problem. The media perpetuate these notions of difference in the separation of social groups of drinkers. The fact that alcohol is a drug that affects the central nervous system, altering thought and behaviour, attracts both amusement and condemnation. It is accepted that alcohol use will remain with us and, as no solution is evident, it must be managed. The real problem is that among the ‘problem managers’ – policymakers and politicians, physicians and clinicians, researchers, educators and trainers and service providers – we also find drinkers. What can be suggested is that future research draw in these other stakeholders.

Diagnosis, clinical expertise and research are critical components of the FASD issue but cannot meet the lifetime support needs of children and families. The consequence of policy decisions based on representations made on the lived experience of families, based on the dominant and authoritative opinions of clinical/research FASD stakeholders, is unfair and elitist, and is leading us down a path to further suppression of the real guts of this issue: the love of alcohol, the existence of an unregulated alcohol industry, a disability that remains unrecognised, families under incredible stress, uninformed service providers, and, most of all, individuals trying to negotiate a life course in the presence of social and political denial. The care and support by parents and families for their children, across the lifespan, may be guided but will not be resolved by diagnosticians or clinicians alone. Until this can occur, science will continue to speak for lived experience. As George Bernard Shaw stated over 100 years ago in *The Doctor’s Dilemma*, there are ‘conspiracies against the laity’ (1906). As the author of this thesis, I have sought to determine the influences that contribute to problem intractability, and to propose a new pathway to the resolution of a wicked problem like FASD. A selection of key events

from the stories of FASD in three countries supports the proposal that solutions have been typically grounded in research, with prevention focused on marginalised, high-risk drinking women.

FASD prevention is dependent on promoting abstinence as the only safe choice amidst controversy over the minimum amount of alcohol in pregnancy to cause harm. Alcohol use in pregnancy has risk consequences for all future parents, and formulation of the problem is associated with possible solutions (Rittel & Webber 1973, p. 161). In this research, it is argued that a different approach to the traditional linear solutions currently favoured by governments and implemented by scientists is required. Fracturing of the problem into small parts, as has been the case, perpetuates problem intractability, and this is likely to continue unless there is equitable representation of a much wider range of stakeholders who might bring other information into the FASD problem system.

A solution-focused approach proposed offers an alternative way of viewing the problem as a system, and the process of resolution as greater than the tendency to seek solutions to parts of the problem rather than the whole. There seems no alternative than reliance on the widest collaboration and open leadership. There are stakeholders currently missing from national FASD collaborative events – pregnant women, those living with the problem, parents and carers, cross-sector system service providers and program managers, to name a few. Given the different frames of reference evident within each of these groupings, accurate representation by spokespersons appointed from a limited pool cannot be assumed.

In respect to bigger problems of which FASD is cast as symptomatic, the role and responses of the alcohol industry to FASD in different jurisdictions, which was not included in the qualitative data, needs to be examined. In addition, gender and how gender discrimination impacts on alcohol use in pregnancy and the risk of FASD are subjects worthy of closer examination. Other topics in the social sciences could be pursued. Birth mothers have asked for clarity of information and more open conversations about alcohol use, generally and during pregnancy; and its impact on fetal development. Does this role fall to health settings or should these conversations take place wherever women are encountered? No understanding been gleaned of what factors deter service providers from delivering this guidance. This current research has limitations but may contribute to assisting future researchers understand the complexity of social issues, particularly as wicked problems are symptomatic of much larger social problems.

There are unanswered questions about the responses of different parent/carer groups to a FASD diagnosis for their children. As the sage Hillel advised, ‘If I am not for myself, who will be for me? And when I am for myself, what am I? And if not now, when?’ In many respects, the voices of individuals and families living with FASD are silent; and their stories have not been appraised as part of this research. FASD is not just a subject on which elite careers are built: it is a profoundly serious

and preventable outcome which is impacting every day on individual lives, and we are not attending to the scope of the problem. There is an opportunity for longitudinal studies on the outcomes for women who have used alcohol in pregnancy or continue to use alcohol, and as the number of adolescents and adults with a diagnosis grows, for a retrospective study of their life experiences.

Governments rely on the work of researchers, and the evidence produced from people considered qualified to know and understand the problem. Often there is an assumption that elites are well placed to represent the interests of individuals living with FASD and their families. As a wicked problem, FASD creates tension between government legislation and alcohol and personal behaviour. In response, policymakers turn to research to provide technical details of the problem; lived experience is excluded. Herein lies the essence of the FASD conundrum and of problem wickedness. Acknowledgement of the long-term time frame needed to address prevention, and the historical, cultural, intellectual, personal and professional obstacles that exist – and including these topics as part of the conversations about FASD prevention – is critical.

APPENDIX 1: INFORMATION SHEET

Title of Investigation

Preventing Fetal Alcohol Exposure in Australia: Tackling a Wicked Problem from the Ground Up

Ethics Approval No. H0011273

Invitation

You are invited to participate in a research study in the above research project. In participating you will have direct face to face contact with Vicki Russell, a PhD student at the University of Tasmania, Australia. The Chief Investigator for this research is Associate Professor Marcus Haward, University of Tasmania.

1. What is the purpose of this study?

This study is part of a PhD research project for Vicki Russell. Limited research has been conducted in Australia to examine why and how FASD and its prevention have not attracted the proactive attention of policy makers in Australia. The identification of factors that have impeded the placement of FASD on the public policy agenda in Australia needs to be explained. Comparison with Canadian experience may, through the identification of relevant policy lessons, suggest ways to circumvent these impediments. This research is relevant given the significant personal, social and economic costs of FASD and the Australian Government's commitment to reducing alcohol use harms in the Australian community.

The study is being undertaken as part of the research required to fulfil the requirements to the PhD degree being undertaken by graduate research student Vicki Russell (School of Government, University of Tasmania).

2. Why have I been invited to participate in this study?

You have been selected for participation in this project based on your involvement with an organisation, department or research institute that is involved in reducing alcohol related harms, prenatal exposure to alcohol or Fetal Alcohol Spectrum Disorder. Your contact details have been obtained from information provided on your organisation's website; from previous communications with the student researcher or from published reference materials.

3. What does this study involve?

Your participation in this research project will be in the form of an interview where you will be asked questions by the researcher. It is important that you understand that your involvement in this study is voluntary. While we would be pleased to have you participate, we respect your right to decline or to choose not to answer any of the questions asked of you. If you decide to discontinue participation at any time, you may do so without providing an explanation. All information will be treated in a confidential manner, and your name will not be used in any publication arising out of the research. All of the research will be kept in a locked cabinet in the office of the School of Government, University of Tasmania.

The interview may extend for more than one hour. And it will take place at a time and location at your convenience. The interview may be recorded using an audio recorder and if this is to happen you will be advised at the beginning of the interview. You have the option to ask for this not to occur and an alternative method instead be used (hand written notes). In either case, an audio or written transcript will be available for you to peruse, edit, modify or withdraw information from.

4. Are there any possible benefits from participation in this study?

Your participation in this study will assist the researcher answer questions regarding (i) why and how FASD and its prevention have attracted the attention of policy makers in Canada; (ii) analysis of nascent grassroots policy initiatives to prevent FASD in Australia; and (iii) key policy lessons from the Canadian FASD prevention experience that may contribute to similar prevention policy development in Australia.

If we are able to take the findings of this small study and link them with a wider study, the result may be valuable information for others and it may lead to prevention initiatives in Australia and Canada.

5. Are there any possible risks from participation in this study?

There are no specific risks anticipated with participation in this study. However, either by purpose or accident, you may supply the information with sensitive or commercial in confidence information. If this occurs you can decide if, and how this information can be used by the researcher.

As a participant in this research project, you may be identifiable, remain anonymous, or choose to be identifiable in the consequent research output. You may choose not to participate on this basis and can choose what information to disclose based on this fact. The project consent form provides a check box to indicate your willingness to be identified. Any issues of confidentiality of information supplied to the researcher will be dealt with as outlined below under *Confidentiality*. Additionally, if any transcript of your participation in this project (interview) is produced, you will have the option to peruse, edit, modify or withdraw any of the information contained within it.

6. Confidentiality

In order to protect the confidentiality of the data collected in the course of this research project you will be informed that you will have the option to enter into an agreement on the use of this data which may include that:

- i. Supervisors and examiners sign commercial in confidence agreements
- ii. The confidential data will be stored in a locked cabinet at the School of Government at the University of Tasmania for at least five (5) years following completion of the thesis. After this, or otherwise, when the information is no longer required, the information will be destroyed by shredding or other appropriate and secure means.

7. Voluntariness

Participation in this research project is entirely voluntary. At any time you can:

- i. Decline to answer any question;
- ii. Withdraw at any time without effect or explanation;
- iii. Withdraw any information you have provided to date.

You must sign a consent form prior to participation in this research project.

8. What if I have questions about this research?

Once we have analysed the information we will be mailing / emailing you a summary of our findings. You are welcome to contact us at that time to discuss any issue relating to the research study. For more information about this research project you can contact:

Vicki Russell Student Investigator 31 Dodgin Street Wynyard 7325 Tasmania Australia Ph 0364422138 Fa- 03 62289145 Email Vicki@den.org.au International Ph +61 3 6442 2138	Associate Professor Marcus Haward Chief Investigator, School of Government and Antarctic Climate and Ecosystems CRC University of Tasmania Private Bag 22, Hobart 7001, Australia Ph 03 6226 2333 Fa- 03 6226 2864 International Ph + 61 3 6226 2333 Fa- + 61 3 6226 2440 Email M.G.Haward@utas.edu.au Marcus.Haward@acecrc.org.au
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9. Statement Regarding Approvals

This study has been approved by the Tasmanian Social Science Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study should contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email human.ethics@utas.edu.au. HREC Ref. No. H0011273.

10. Results of Investigation

The results of this research will be presented in a thesis submitted to the University of Tasmania. After this thesis has been assessed, copies will be available in the University of Tasmania library on the UTas EPrints repository (servicedesk@utas.edu.au) or (+61 3 62261818). A copy of any paper which is published as a result of this research will be forwarded to the participants. The participant will be given a copy of the Information Sheet and Informed Consent to keep for their records.

Thank you for taking the time to consider this study. If you wish to take part in it, please sign the attached consent form. This information sheet is for you to keep.

Associate Professor Marcus Haward

Vicki Russell

Chief Investigator

Student Investigator

APPENDIX 2: CONSENT FORM

Title of Project: Preventing Fetal Alcohol Exposure in Australia

Ethics Approval No. H0011273

1. I have read and understood the 'Information Sheet' for this project.
2. The nature and possible effects of the study have been explained to me.
3. I understand that the study involves participating in an interview regarding my experience and/or opinion about the prevention of prenatal exposure to alcohol and Fetal Alcohol Spectrum Disorder and that this interview may take at least an hour.
4. I understand that participation involves the risk(s) that commercial in confidence information may be imparted to the researcher and that if this occurs I have the choice of whether this information can be used by the researcher. If I consent to this information being used, I can request that this information is protected through various measures, as outlined in the Information Sheet.
5. I understand that I will be given the opportunity to peruse a transcript of a tape of my interview at which time I can edit, modify, or withdraw any of the information contained within it.
6. I understand that all research data will be securely stored on the University of Tasmania premises for at least five years, and will then be destroyed when no longer required.
7. Any questions that I have asked have been answered to my satisfaction.
8. I agree that research data gathered from me for the study may be published provided that I will not be identified as a participant unless I specifically agree (see checkbox below).
9. I understand that the researchers will maintain my identity confidential and that any information I supply to the researcher(s) will be used only for the purposes of the research.
10. I agree to participate in this investigation and understand that I may withdraw at any time without any effect, and if I so wish I may request that any data I have supplied to date be withdrawn from the research project.

Name of Participant:

Signature:

Date:

Statement by Investigator	
<input type="checkbox"/>	<p>I have explained the project & the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation.</p> <p>If the Investigator has not had an opportunity to talk to participants prior to them participating, the following must be ticked.</p>
<input type="checkbox"/>	<p>The participant has received the Information Sheet where my details have been provided so participants have the opportunity to contact me prior to consenting to participate in this project.</p>
<input type="checkbox"/>	<p>The participant has specifically agreed to be identified.</p>

Name of investigator Vicki M Russell

Signature of investigator _____ Date _____

APPENDIX 3: LIST OF RECOMMENDATIONS ‘FASD: THE HIDDEN HARM: INQUIRY INTO THE PREVENTION, DIAGNOSIS AND MANAGEMENT OF FETAL ALCOHOL SPECTRUM DISORDERS.’ (STANDING COMMITTEE ON SOCIAL POLICY AND LEGAL AFFAIRS, 2012

Recommendation 1: The actions set out in this report should constitute the Commonwealth Government’s National Plan of Action for the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders (FASD). This FASD National Plan of Action should be publicly released by 1 June 2013p. 147

Recommendation 2: The Committee recommends that the Commonwealth Government immediately establish an ongoing Fetal Alcohol Spectrum Disorders (FASD) Reference Group reporting to the relevant Commonwealth Government Ministers, consisting of a select group of appointed practitioners, professionals and stakeholders who are experts in the field of prevention and management of FASD. The role of the FASD reference group would be to oversee and advise on the FASD National Plan of Action

Recommendation 3: The Committee recommends that the Commonwealth Government publicly report: within 12 months on the progress of the implementation of a national Fetal Alcohol Spectrum Disorders (FASD) diagnostic and management services strategy, a critical element of the FASD National Plan of Action, and v within five years on the progress towards eliminating FASD in Australia.

Recommendation 4: The Committee recommends that the Commonwealth Government work with the National Health and Medical Research Council and professional peak bodies to ensure that all health professionals are: fully aware of the National Health and Medical Research Council Guidelines that advise women not to drink while pregnant; have alcohol consumption impacts on pregnancy and the developing fetus incorporated into all general practice and midwifery training; trained in discussing the National Health and Medical Research Council Guidelines and alcohol consumption with women; and skilled in asking women about alcohol consumption and recognising and responding to women at risk. By 1 January 2014, all health professionals, including sexual health advisors, midwives, general practitioners and obstetric professionals should be promoting the consistent message that not drinking while pregnant is the safest option, in line with the National Health and Medical Research Council Guidelines.

Recommendation 5: The Committee recommends that the Commonwealth Government establish mechanisms for health professionals to record women's alcohol consumption during pregnancy, or at the time of birth for women who have not presented for prenatal care, and to ensure such information is recorded in midwives data collections or notifications across Australia.

Recommendation 6: The Committee recommends that the Commonwealth Government implement a general public awareness campaign which promotes not drinking alcohol when pregnant or when planning a pregnancy as the safest option, consistent with the National Health and Medical Research Council Guidelines. Specific awareness campaigns should be developed to target youth and Indigenous communities. Nationwide campaigns should be started no later than 1 July 2013. -i-

Recommendation 7: The Committee recommends that the Commonwealth Government mandate a health advisory label advising women not to drink when pregnant or when planning a pregnancy to be included on the packaging of all pregnancy and ovulation testing kits. These labels should be in place by 1 October 2013.

Recommendation 8: The Committee recommends that the Commonwealth Government raise with the States and Territories the critical importance of strategies to assist Indigenous communities in managing issues of alcohol consumption and to assist community led initiatives to reduce high-risk consumption patterns and the impact of alcohol.

Recommendation 9 The Committee recommends that the Commonwealth Government work with State and Territory governments to identify and implement effective strategies for pregnant women with alcohol dependence or misuse

Recommendation 10 The Committee recommends that the Commonwealth Government seek to include health warning labels for alcoholic beverages, including a warning label that advises women not to drink when pregnant or when planning a pregnancy, on the Legislative and Governance Forum on Food Regulation's December agenda. The Commonwealth Government should determine the appropriate format and design of the labels by 1 March 2013, to assist the alcohol industry in adopting best practice principles and preparing for mandatory implementation. --

Recommendation 11 The Committee recommends that the Commonwealth Government mandate the range of health warning labels for alcoholic beverages as decided by the Legislative and Governance Forum on Food Regulation. v The warning labels should consist of text and a symbol and should be required to be displayed on all alcohol products, advertising and packaging by 1 January 2014; v The minimum size, position and content of all health warning labels should be regulated; and v The

introduction of mandated warning labels should be accompanied by a comprehensive public awareness campaign.

Recommendation 12 The Committee recommends that the Commonwealth Government commission an independent study into the impacts of the pricing and availability of alcohol and the influence of these factors in the changing patterns of alcohol consumption across age groups and gender. The study should be completed by 1 October 2013.

Recommendation 13 The Committee recommends that the Commonwealth Government commission an independent study into the impacts and appropriateness of current alcohol marketing strategies directed to young people. The study should have regard to these strategies and the volume and frequency of alcohol consumption among young people, the links being made between alcohol and sport, the efficacy of efforts to promote responsible drinking behaviours, and the adequacy of current regulations to respond to marketing through digital platforms such as the internet, social media and smartphones. The study should be completed by 1 October 2013.

Recommendation 14 The Committee recommends that, following the completion of the study into the pricing and availability of alcohol and the study into alcohol marketing strategies, the Commonwealth Government develop a National Alcohol Sales Reform Plan aimed at reducing the harms caused by irresponsible alcohol consumption across Australia. --i 4 Diagnosis

Recommendation 15 The Committee recommends that the Commonwealth Government expedite the rollout of the Fetal Alcohol Spectrum Disorder (FASD) diagnostic instrument and the development of a training and user manual. These should be available for use by 1 October 2013. Following the rollout, the Commonwealth Government should establish a mechanism to collect and monitor diagnostic data in order to assess the effectiveness of prevention strategies and patterns of FASD occurrence.

Recommendation 16 The Committee recommends that the Commonwealth Government develop and implement a national Fetal Alcohol Spectrum Disorders (FASD) diagnostic and management services strategy. This strategy should be monitored and informed by the FASD Reference Group, and should establish capacity by 1 July 2014 for the following: v awareness among all general practitioners and child and maternal health professionals of the causation and clinical features of FASD and the importance of early diagnosis and intervention; v establishment of a model for diagnostic services such that regional as well as metropolitan areas are properly serviced; and v identification of effective methodologies of management including international best practice. 5 Management needs

Recommendation 17 The Committee recommends that the Commonwealth Government develop educational material to raise awareness about Fetal Alcohol Spectrum Disorders (FASD). These materials should be monitored and informed by the FASD Reference Group. In particular, targeted training and materials should be developed for: v special education teacher aides and class teachers; v parents, foster carers and foster care agencies; v police and court officials; v youth workers and drug and alcohol officers; and v officers in correctional facilities and juvenile detention centres.

Recommendation 18 The Committee recommends that the Commonwealth Government include Fetal Alcohol Spectrum Disorders in the List of Recognised Disabilities and the Better Start for Children with a Disability Initiative. 148 Parliament of Australia, Standing Committee on Aboriginal and Torres Strait Islander Affairs, *Doing Time – Time for Doing: Indigenous youth in the criminal justice system*, June 2011, p 103. 148 FASD: THE HIDDEN HARM

Recommendation 19 The Committee recommends that the Commonwealth Government recognise that people with Fetal Alcohol Spectrum Disorders have, among other disabilities, a cognitive impairment and therefore amend the eligibility criteria to enable access to support services and diversionary laws.

APPENDIX 4: QUALITATIVE CONTENT ANALYSIS – CODING

Question 2: What factor/s do you believe have been the most influential in developing the issue?		
Participant No.#	Interview data	Coding
BS0101	From my view in Indian Health, as we became more aware that the effects we were seeing in children were directly related to spectrum disorders, and that these disorders were completely preventable, the interest in prevention and intervention increased. I believe there were also cultural and political developments as well, particularly in Indian Country, when tribal programs and communities became increasingly aware of the severity of the problem and the long term, chronic effects, the communities themselves started taking direct public health action to reduce rates and prevalence.	Demand for problem attention – impact
MD0102	‘In aggregate, the research on FASD among adolescents and adults has used a variety of diagnostic schemas leading to inconsistencies in the diagnostic criteria and the clinical research outcomes.’	Medical - different schemas, inconsistencies – diagnosis Research - inconsistencies
RS0103	Learnt a lot about the content of FASD in the early days and believes champions are needed to take the issue on, to promote the issue and Ken Warren is an example of such a champion. He is the A/Director of NIAAA. Dr Warren developed the FASD program at NIAAA and allocated a funding stream for the issue. Identifying the issues and developing a specific funding stream. Develop a whole movement with the science that supports it and having researchers who are able to learn more about the problem Demonstrate the problem is important enough to pay attention to. Use epidemiological studies – monitoring how many women are drinking and the prevalence of FASD among children. In the early days (1992), we looked at how many women are drinking and how much women were drinking. This led to media attention and raised public concern. The media were able to continue on that theme. It was important to conduct ongoing research on how many women were drinking who were not pregnant so that women could be reached upstream. Parents of FASD kids are able to tell their stories and the extent to which FASD affects lives in the US. These stories are authentic and parents are not necessarily biological	Advocacy - problem severity Collaboration and co-ordination ICC_FASD, CDC National Taskforce of medical and NGO Women - alcohol, stories, research Future priorities – champions inside government, specific policy stream, support of scientific evidence Funding – resources/events

	<p>parents. They knowingly or not knowingly advocated a vision without knowing all the details.</p> <p>Selected members of Congress have been important too. People like Tom Daschle and tribal groups in South Dakota. These people were strong advocates on the floor of Congress, 'help lay in on the issue' and gain funding for an agenda. The FASD Agenda probably gained momentum through the formation of the Interagency Committee on FASD, formed in 1995-96. The IC-FASD brought agencies together. In 1999, the CDC convened a National Taskforce on FASD which brought together experts from the field and established liaison across professions like obstetrics and paediatrics and NOFAS. A database of materials and resources and assistance to help people navigate the system were developed and events like the March of Dimes. Federal agencies engaged in the issue through the ICC-FASD and standing members reported back. This effort was the foundation of bringing federal agencies closer together; funding for work to be done was achieved. ICC-FASD is required to report on programs and working groups on strategies and achievements.</p>	
CH0104	<p>Absolutely prevention. As a priority, we need to recognize FASD affected individuals but this is difficult because of difficulties. We will fail them if we don't and identifying affected individuals prevents intergenerational impact and future exposed pregnancies. In 2005, I read a series of articles on FASD and Dianne Malbin came to present on FASD and light bulbs went off. I have always been a champion for the underdog and 'people who are not being seen.' In 2007, we made a DVD called 'Helping babies from the bench.' This was seen by Larry Burd and he was sent a copy of the DVD. We also pushed the 0-3 years' agenda.</p> <p>The PCAP 'Difference Game' asks 'it would make a difference if...' rather than saying to mothers, 'this is what you have to do to get your kids back.' Pre-institute – Larry and Therese spoke. There was also Ritzwan Shah, a pediatrician and Claire Coles who later met with staff for ½ day.</p> <p>In 2010, Larry and Ed Riley presented and the latter spoke about the brain and FASD. Not sure what will be happening in 2011. 0-3 years' journal article on FASD. American Bar Association – Center for Children and the Law and Maternal Health. There was funding but we were squeezed out. Larry and Katie Kelly wrote a brief but it was declined as it was not in the correct format. It was targeting legals.</p>	Women - future exposed pregnancies, what women need to do.

RS0105	<p>The least point has been labelling on alcohol beverages. There is a certain level of awareness and physicians are talking to women. I have noticed liquor commercials – hard liquor has replaced beer ads during sporting events on TV.</p> <p>In general, I think there is societal awareness of the harms of alcohol on health. The Feds have a high degree of awareness and more funding is needed. Currently \$800,000 is invested in FASD compared with \$30 million invested in autism.</p> <p>There is stigma. FASD is not a popular problem to be associated with for policy makers. Congress tells us where to spend allocated money. This can lead to disconnect with congressmen and some agencies have not taken on FASD. Consequently, there are a lot of people labelled autistic who are FASD.</p>	<p>Demand for problem attention - public awareness</p> <p>Medical – risk message</p> <p>Alcohol industry – labels least influential</p>
HP0106	<p>FASD is not the result of a population groundswell. It had been about small groups of interested federal public servants like Ken Warren.</p> <p>The ARC has a bigger presence and funding. NAMI – people are very reticent. Scientists plus federal public servants plus small advocacy group. The biggest influence was Senator Tom Daschle but the issue has over time, been slowed up by lack of funding.</p>	<p>Demand for problem attention – not population groundswell – federal public servants</p>
MD0107	<p>Collaboration since 2001 between NIH, NIAAA, SAMHSA has built some traction and attention for women, children and families.</p> <p>Collaboration occurs with the not for profit sector – NOFAS; drug advocacy groups and expert panels (including researchers, affected individuals and those in recovery). ‘All women are at risk for an alcohol exposed pregnancy.’ This includes Caucasian college graduates who have alcohol issues,</p>	<p>Women – all at risk</p> <p>Collaboration – focus of national institutions</p>
RS0108	<p>Three events have been detrimental:</p> <p>a) About the same time FAS became an important public health issue, the AIDS epidemic overshadowed all other public health issues;</p> <p>b) FASD had a second resurgence and the autism epidemic became the focus of much of the available discretionary spending for state or provincial governments;</p> <p>c) The inability of the FAS field to move beyond FAS to the more typical manifestation of FASD which is birth defects, mental disorders, substance abuse and developmental disabilities. Right now we seem trapped in the grip of dysmorphology which is of little use in the majority of cases of FASD. Thus, we continue to increase</p>	<p>Demand for problem attention - incidence</p> <p>Cost – lifetime care is large</p> <p>Medical and diagnosis – focus on dysmorphology, inability to move beyond typical manifestations</p> <p>Prevalence – recurrence rate exceptional,</p> <p>Funding - problem competitive, cross service systems</p>

	<p>the size and cost of a system which is able to diagnose less than 15% of affected people, and is too expensive to support for a common condition like FASD.</p> <p>Events have been helpful:</p> <p>The lifetime-cost of care is so large that FASD competes well with other disorders for funding.</p> <p>Most of the cost of care is covered by publicly funded funds, and with a thoughtful explanation, most legislators can understand how this single issue increases utilization of nearly all state or provincial service systems.</p> <p>The recurrence rate is exceptional and this issue forces providers and funders to confront the importance of prevention, early detection and effective substance abuse treatment in this disorder.</p>	
BP0109	Animal research & birth mothers who are able to tell their stories in a believable and accurate way (important they come across as ‘mainstream-everyday people’).	Women – birth mother stories
RS0110	<p>There are lessons that can be learned from the data collection process on fatalities from motor vehicle accidents. All fatalities are tested for alcohol and data collected locally is entered in a national data base. We know where fatal accidents are happening across the US and this enables us to look at other variables. This data has revealed the alcohol related deaths are higher than tobacco.</p> <p>Increasing the drinking age = a 20-year study on 16 to 20-year-old.</p> <p>WHO global strategic plan on alcohol was ratified – 6 conferences – 38 policies. Those involved in FASD could follow the 38 policies in terms of fetal alcohol legislation.</p> <p>There are multiple adverse life experiences,</p>	Government – policy - follow WHO alcohol strategy
NG0111	NIAAA – clinical and biomedical research papers over 40 years. Early work led to evidence based US Surgeon General warning in 1989, reviewed 2005 and unchanged	Collaboration – focus of national institutions, research
ET0112	<p>Brain function/dysfunction over past 50 years – impacted on thinking about behaviour..</p> <p>Contributes to understanding of parent issues (neurobiology of addictions) and children’s’ issues (neurobehavioral symptoms)</p> <p>Understand differently the meaning of behaviors and how to respond differently and effectively</p> <p>Historically, no solution for addiction and no solution for people with neurobehavioral differences – instead, reaction to behaviour has been ‘from benign neglect to active persecution, indicating shared ignorance with associated fear and reactivity.’</p>	<p>Demand for problem attention – increasing numbers, cannot ignore</p> <p>Alcohol - no solution to addiction</p> <p>Medical profession and the diagnosis – didactic approach and behaviour, no solution, increasing numbers as diagnostic capacity grows</p> <p>Prevalence – increasing numbers</p> <p>Future - planning for identification to exceed</p>

	<p>A solution provides opportunity for identification. No solution equals no problem.</p> <p>Actual number 'are so great as to be unbelievable,' says Sterling Clarren MD – impossible to ignore</p> <p>Claim that FASD leading cause of intellectual disabilities notable given lack of diagnostic capacity in virtually all countries</p> <p>Increasing number of children and adults are being recognised</p> <p>Numbers will increase as diagnostic capacity increases</p> <p>Planning for inevitable stage where identification exceeds capacity to provide support.</p>	capacity to provide support
AP0213	<p>Shame and blame is reducing</p> <p>Adoptive mothers need to hear birth mother stories People with passion – advocates and parents including government parents at 'very senior levels' – the latter are nameless parents and their children did not just 'drop out of the sky.'</p> <p>Numbers of affected individuals and economic cost acknowledged but telling the human story is critical</p>	<p>Stigma/discrimination – reducing</p> <p>Advocacy – adoptive mothers need to hear birth mother stories, people with passion (government parents)</p> <p>Prevalence - acknowledged</p> <p>Cost - acknowledged</p>
RS0214	<p>Lack of linkages across child welfare, health and justice, lack of conjoint resources, lack of collaborative case management</p> <p>Lack of systemic responses to women, children and families with co-occurring alcohol and other drug use, mental health and parent themselves affected by FASD</p> <p>Lack in child welfare 'in FASD, complexity of substance abuse and intergenerational family trauma'</p> <p>Non-inclusion of fathers and blameworthiness of mothers 'extremely vulnerable to judgments of society'</p>	<p>Systems and service provision - lacking cross linkages</p> <p>Women – blamed, judged</p> <p>Stigma/discrimination – non-inclusion of fathers</p>
GP0215	<p>Strong grassroots movement in Alberta, a number of communities driving local prevention and support initiatives, political appetite to address the issue</p> <p>Minister of Children's Services – Iris Evans – secured funding for provincial and local initiatives</p> <p>Close proximity to Uni of Washington and Dr Sterling Clarren – trained or influenced local service providers</p> <p>PCAP mentoring program</p>	<p>Advocacy– grassroots, local initiatives, political champions, proximity to Uni of Washington.</p> <p>Women – PCAP</p>
AP0216	<p>Diagnosis must occur simultaneous with family support and planning</p> <p>'As the message about alcohol use in pregnancy got through to the public, reduced alcohol intake meant less signs of FAS in children and this complicated the outcome</p>	<p>Advocacy and demand for problem attention - conference</p> <p>Stigma-discrimination – FASD only part of who</p>

	<p>for children – ARND.’</p> <p>A centre for diagnosis – took 7 years to establish – multidisciplinary team. Parents who seek diagnosis are grieving for the cost of drinking</p> <p>Dr Asante in BC</p> <p>Birth mother stories – social determinants influence personal learning – translated to community work</p> <p>Messages – care for women and families. Fathers too.</p> <p>Organised conference 1995 – 50 organisations supported, 300 attended. A FASD Committee formed – raise awareness – signage, posters, educate young people.</p> <p>Training at Uni of Washington</p> <p>‘Multidisciplinary teams including a psychologist, a speech and language therapist, a child psychiatrist and OT. Multidisciplinary teams were at first ‘pretty naïve’, however, they were good professional educators and included education as a component of their work and educated everyone. The child comes in for full assessment and the results are discussed with the family team (this is based on the findings and tells families what to do and what is needed to support the child). It is also about telling a parent what can happen ‘if you continue to drink’ and the effect this can have on subsequent children. The FASD diagnosis ‘identifies strengths and we state that FASD is only part of what your child is.</p>	<p>the child is</p> <p>Medical profession and the diagnosis – plus family support and planning, increased presentation of ARND, multidisciplinary team</p> <p>Systems and service provision - training</p>
RS0217	<p>‘The public health message has to say alcohol is a ‘risk’ in pregnancy not a ‘certain.’</p> <p>The message needs to support women to think it through, not just in pregnancy, but in all of her life.’</p> <p>Government recognised problem would not be solved by one service (like health) – contracted for FAS Community Action Guide developed and Strategic Plan</p> <p>Strategic Plan – three workers – paediatrician, health promotion and women’s treatment service – worked together to formulate from a multi-sectoral view which respected difference – in planning stage, set down principles and determined intent. Focus on identifying points of collaboration.</p>	<p>Collaboration – Strategic Plan</p> <p>Women – supportive public health message</p> <p>Systems and service provision – not one service.....</p>
SP0218	Three key champions - Dr Chris Locke, Dr. Liz Whynott and Nancy Poole	Collaboration – champions named
LP0219	<p>The social mechanism of not liking those not like us...see: e. Becker’s DENIAL OF DEATH</p> <p>Invisibility ‘tracks no political heat’ Assume all brains are alike – learn from mistakes,</p>	<p>Stigma-discrimination – not liking those not like us</p> <p>Government - invisibility ‘tracks no political heat;’</p>

	<p>learn from the mistakes of others – we say, I would not do that. Lack of critical thinking, policy fails to recognise damage, legal drug – prohibition a failure, glacier of ignorance needs education</p> <p>‘most FASD conferences are a waste of time because we are speaking to the converted, singing to the choir...we don’t reach the community’</p> <p>Educators at local level and can talk about the permanency of brain based birth defects</p>	<p>fails to recognise damage, ignorance</p> <p>Systems and service provision - - assume all brains alike</p> <p>Workforce development – conferences a waste of time, educators at local level</p>
BP0220	<p>Fetal Alcohol Support Network-expanded support groups across Canada and United States</p> <p>Internet – most influential single force</p> <p>No longer can information be controlled and limited by media and academic institutions</p>	<p>Advocacy – support groups, use of internet, information shared and not controlled</p>
ET0221	<p>Accurate information on sensory, cognitive and physical variables, all given respectfully</p>	<p>Education</p>
SP0222	<p>FASD Committee formed in 1994 – build understanding and raise awareness – targeted as many women populations as possible</p> <p>Promote politician awareness – ‘the issues and solutions is critical at local, provincial and national levels.’ If politicians not interested, target spouses</p> <p>living in a rural area it is the social context of women allowed to drink in bars</p> <p>Residential schools</p> <p>Service delivery to women – utilise the PCAP model adapted for the region</p>	<p>Advocacy - promote politician awareness</p> <p>Collaboration and co-ordination - local</p> <p>Women – legislation change allowing drinking in bars</p> <p>Aboriginal – residential schools</p> <p>Systems and service provision - PCAP adapted locally,</p>
BP0323	<p>Will need support from policy makers and government officials – who will see the dollars it will cost and ‘show cause’ as to why they haven’t picked up on this 13 years ago.’</p> <p>Grassroots advocates – NOFASARD, us lot. People with passion, determination, promoting support for families</p>	<p>Demand for problem attention – NGO, support for families</p> <p>Government and funding – support, recognise cost</p>
RS0324	<p>Some Aboriginal parents are brave enough to advocate</p> <p>The burden of intergenerational use of alcohol and too many families lacking power, knowledge or inclination to do anything about.</p> <p>Attitude to alcohol is downplayed and ‘not seen in a sinister light.’ Warnings about alcohol use are viewed as ‘tantamount to treason’</p>	<p>Alcohol - intergenerational, attitude downplayed, warnings are like treason</p> <p>Aboriginal – some brave enough to advocate, others lack power, knowledge or inclination</p>
RS0325	<p>Me, becoming educated when not taken seriously as an Aboriginal woman and knowing there is failure to consult in a culturally sensitive manner</p>	<p>Aboriginal – worker education</p> <p>Systems and service provision - failure to consult</p>

MD0326	international developments 'increased recognition that alcohol is a major social issue relevant to all in our society' Groundswell from research, advocacy groups	Advocacy - researchers and advocacy groups Collaboration – international Alcohol – a major issue
RS0327	Sue Miers and researchers and impact on health professionals	Advocacy – key advocate, researchers Systems and service provision – impact on health professionals
AP0328	Parent persistence Personal learning and separating bad behaviour from FAS and service provider awareness improved 'I can remember when we going through IVF and there were 14 women in the IVF Clinic and a pub down the road. We would share wine and none of us knew the risks.' I am an adoptive mother and have no real idea how it might be for a birth mother. I think it would be different, there would be stigma. I think that if I had been able to fall pregnant, it could easily have been me that gave birth to a child with FASD.	Demand for problem attention – parent persistence Systems and service provision – has improved Women – stigma on birth mothers as opposed to other parent status
SP0329	Inconsistent messages to women The National Alcohol Guidelines 2009 Evidence of harm is lacking	Systems and service provision – inconsistent messages Government – national alcohol Guidelines Research – evidence lacking
RS0330	Technology – internet 'the voice of articulate, affected adults (parents) which changes the argument, helps push this issue, in the media' and Aboriginal people who have advocated strongly in their communities Better detection in addition to the more obvious features of FAS Statistically low numbers mean research difficult in general population	Advocacy – articulate adults, Aboriginal advocates Prevalence – poor rate of detection across spectrum, low numbers recorded Research – difficult in general population
RS0331	'People who have stuck with it in the longer term...tough when they started out but the issue has gained momentum over time. Others came in along the way.'	Advocacy and demand for problem attention – people who have stuck in long term, other joined
AP0332	Understanding of FAS in Canada Establishment of NOFASARD; Prompted meeting with Professor Eric Haan who then shared with the Australian Paediatric Surveillance Unit including Professor Carol Bower and Professor Elizabeth Elliott.	Advocacy and demand for problem attention – NGO Collaboration – international Medical profession and the diagnosis – shared knowledge

Question 3: What factor/s do you believe have been the biggest impediment or challenge in the development of this issue?		
Participant No. #	Interview data	Coding
BS0101	Challenge of screening during pregnancy and providing treatment services for alcohol dependent women Use is influenced by economic, social, political, cultural factors.	Medical profession and the diagnosis – challenge of screening and providing treatment services
MD0102	Spectrum problematic, some medical professionals do not know how to diagnose, suspect lower socio-economic disorder. Individuals don't respond to standard treatments, outcomes criminal justice and group homes Research conducted outside United States in higher prevalence nations or in the United States with Plains Indians	Medical profession and the diagnosis – diagnosis problematic, some do not know how to diagnose Research – lower socio-economic disorder, in higher prevalence nations
RS0103	physician disbelief re alcohol as causal or that disorder is problematic – not advise women of risk	Medical profession – disbelief, not advise women of risk
CH0104	Label certain population groups more easily as having a 'drug' problem. A story of historical trauma v privilege. Disability policy reflects risks of illicit drug use, not alcohol. 0-3 years journal article on FASD. American Bar Association – Center for Children and the Law and Maternal Health. There was funding but authors were squeezed out.	Stigma-discrimination – labelling some populations more easily Government – policy reflects illicit drugs, not alcohol
RS0105	Alcohol – culture of drinking	Alcohol – culture of drinking
HP0106	Diagnosis – lack of agreement on the spectrum, connection with learning problems, connection with socially acceptable alcohol use Difficulty of 'D's' effects measuring prevalence rate and demonstrating need to decision makers.	Medical profession and the diagnosis – lack of consensus on spectrum, learning problems, lower risk alcohol use Prevalence, cost – spectrum limits accurate measurement, demonstrate need to policy makers
MD0107	The need to collaborate to get the big picture. Diagnosis – undiagnosed or misdiagnosed – labelled ADD/ADHD Rationale of not stigmatising women Work unsustainable, inadequate care – relapse Screening has not translated to all settings Denial – collective unconsciousness about drinking	Alcohol – collective denial Women – need better care to avoid relapse Medical profession and the diagnosis – undiagnosed, misdiagnosed, labelled ADD/ADHD Systems and service provision – unsustainable work, inadequate care of women, screening not undertaken in all settings, rationale of not

		stigmatising women
RS0108	Diagnosis – the full spectrum is complex and costly when expanded and not just FAS. Missing women who typically are not accessing the health care system. FASD is in competition with other conditions. A child with FASD	Medical profession and the diagnosis – spectrum is complex, diagnosis costly Research – missing women who are not accessing health care Funding – in competition with other conditions
BP0109	Stigma and mixed messages	Stigma-discrimination Systems and service provision – mixed messages
RS0110	No response	
NG0111	Discrimination – the name stigmatises mother, different standards for different groups Diagnosis – discretionary choice to seek alternative condition, problematic and not in DSM Individual choice is policy position and you cannot present to industry as opposed	Medical profession and the diagnosis – alternative condition is a choice for some Stigma-discrimination – name FASD stigmatises mother, discretionary application of condition Government – policy position supports individual choice re alcohol
ET0112	Consider the parent with addiction Prejudice, stereotypes, bias and judgement – affects minorities by dominant groups Fail to recognise FASD is a social issue or the magnitude of social problems Cultural context - common shared values and beliefs about alcohol use define problem definition and no solution In professional practice - evokes strong feelings, personal stories bound up in fear, personal trauma with few seeking healing and recovery and addictions Deviant if choose not to drink Teachers, legislators, doctors, social workers drink too – denial well-defended – status quo Individual with FASD – interventions are grounded in learning theory/behaviour based interventions rather than awareness of brain-based condition – lost opportunities to offer help Programs, policy, resource allocation and legislation reflect knowledge, values and beliefs – barriers to prevention	Alcohol – consider parent with addiction, common shared values about use define problem definition and no solutions, deviant if choose not to drink, professionals drink too leads to denial Stigma-discrimination – prejudice, bias, judgment affects minorities Government – policy barriers, reflect knowledge, dominant values and beliefs Systems and service provision – in professional practice, alcohol evokes strong feelings, interventions based in learning theory – lost opportunities to help
AP0213	DENIAL – a vested interest Problem too big with no solution - Problem too small – no solution needed	Demand for problem attention - met with denial Alcohol/industry - industry investment, middle

	<p>Problem too small – alcohol industry - industry invests – claims interest and supportive</p> <p>Need to know what happens to kids in long term post diagnosis</p> <p>lacking – definitive answers wanted on low risk which will never be simple.</p> <p>Discrimination –FASD is as racial issue - middle class denies social drinking as unrelated to FASD - lacks understanding of social drinking more than low risk drinking</p>	<p>class denies social drinking risk</p> <p>Stigma-discrimination – FASD a racial issue</p> <p>Research – what happens post-diagnosis, definitive answers wanted re low risk drinking</p>
RS0214	<p>Child welfare obvious response but workers may have no knowledge or understanding of FASD – Troubled and traumatized families high risk of further trauma and judgment.</p> <p>Mandatory training essential – integrated family based response needed across jurisdictions.</p> <p>Greater attention through Aboriginal lens needed, culturally sensitive prevention effort at macro level.</p> <p>Assigned workers may have no knowledge or understanding of FASD and families further traumatized</p>	<p>Aboriginal – greater attention to cultural lens at macro level</p> <p>Systems and service provision – child welfare - designated worker may have no knowledge or understanding, high risk families subjected to further trauma and judgment</p> <p>Future – mandatory training essential</p>
GP0215	<p>Messages may have added to discrimination against those living with FASD</p> <p>Less in social marketing – more on supports for workers – we were not prepared</p>	<p>Stigma and discrimination – messages may have increased burden</p> <p>Systems and service provision – more supports for workers who were not prepared</p>
AP0216	<p>Love of alcohol</p> <p>Assessments are costly.</p> <p>Stigma is social</p>	<p>Alcohol – love</p> <p>Medical profession and the diagnosis – assessment is costly</p> <p>Stigma and discrimination – a social construct</p>
RS0217	<p>Missed opportunities e.g. social worker attached to obstetrics clinics. Child and family need a diagnosis + social supports – paraprofessionals working respectfully.</p> <p>Didactic - child v women’s health. Good v bad guy. Child innocent which means mother guilty is default position. Systems built on this notion but as child’s needs are met through parent/s we cannot consider child without considering parents.</p> <p>Prevention is tough – based on medical model – ironically, once born problem is less medical. Healthcare system is more powerful.</p> <p>Diagnosis – know about brain mechanisms but too few people do this work.</p> <p>Overall, there is ambivalence about alcohol, about women’s equality versus the rights of the child; and the medical model versus a biosocial model.</p>	<p>Women – child v women’s health, mother guilt is default position, no safety for women to have conversations</p> <p>Medical profession and the diagnosis – missed opportunities, once child born is less medical, too few do the work, prevention is based in medical model, ambivalence re alcohol, women’s equality v rights of child, medical v a biosocial model</p> <p>Prevalence- no good evidence</p> <p>Research – interventions, lack of safety for women</p>

	<p>No good evidence on prevalence, incidence or how to mobilise people compared to other conditions. Need research on interventions.</p> <p>Have not created safety for conversations about alcohol use – stigma.</p> <p>Lack of safety makes diagnosis and research difficult.</p> <p>Apprehend children without putting resources into parents – becomes adversarial – misogynist.</p>	<p>to disclose makes research difficult</p> <p>Systems and service provision – built on notion of child innocence which means mother guilty, adversarial and misogynist</p>
SP0218	<p>Some providers take sides fearing a choice will fail to protect the child.</p> <p>Didactic - focus on child without mother - leads to blaming and shaming the mother – creates barriers to help seeking and moral stigma. Prevention is about valuing mother and child together,</p> <p>Women - broader determinants of health need to be addressed</p>	<p>Stigma-discrimination - moral</p> <p>Systems and service provision – some fear support of child will blame mother, creates barriers</p> <p>Future – determinants of women’s health addressed</p>
LP0219	Alcohol industry – influence on uneducated public,	Alcohol industry – public influence
BP0220	<p>massive denial - no-one has an alcohol problem and discomfort means don’t talk about it (alcohol problem)</p> <p>Too few physicians know how to diagnose, do not want to offend mother by asking about drinking.</p> <p>Diagnosis – autism, Aspergers, ADD/ADHD...but avoid alcohol label – consequence is no intervention and/or support – trauma with bad results.</p> <p>Too few physicians know how to diagnose, do not want to offend mother by asking about drinking.</p> <p>Diagnosis – autism, Aspergers, ADD/ADHD...but avoid alcohol label – consequence is no intervention and/or support – trauma with bad results.</p>	<p>Alcohol – massive denial.....</p> <p>Medical profession– too few can diagnose, not offend mother re drinking, avoid FASD label as this is about alcohol, wrong conditions diagnosed, no intervention or support, re-traumatised</p>
ET0221	<p>Lack standards and consistency in interviewing women re substance use in pregnancy.</p> <p>Screening tools intimidating.</p>	Women – screening tools intimidating
SP0222	<p>Direct services for women – hardest to reach and highest risk women who are not connected to services</p> <p>Stigma is created by professionals who make judgements</p> <p>Lack of. Prevention efforts are timely and costly. Prevention not something which can be done off the side of one’s desk</p>	<p>Stigma-discrimination – by professionals who make these judgements</p> <p>Systems and service provision – highest risk women are hardest to reach, not connected to services, - prevention timely and costly, not done off side of desk</p>
BP0323	people do not want to see the negatives of drinking and the alcohol industry is subversive	<p>Alcohol – culture, industry subversive</p> <p>Research – finding lower limit of safe alcohol</p>

	finding safe lower limit of alcohol a ridiculous waste of money...results confound people 'don't believe, to accept a condition they know little about – arrogance.	waste of funds, results confusing
RS0324	why are they ignoring it? Their official representative bodies need to ask that. ignorance and denial continues – renders 'baby, child or adult with FASD invisible.' difficult advocating when doctors deny FASDs – 'I even question myself...does this really exist or am I imagining it? I question my own intelligence and maybe that is what the medical hierarchy wants us to do.' medical profession must take on FASD awareness prevention, diagnosis and management. Public opinion will not happen unless doctors drive it.	Advocacy – am I imagining it? Medical profession – denial, ignorance should be questioned by professional bodies, ignorance renders FASD invisible Future - prevention, diagnosis and management – public opinion will change if doctors drive it
BP0325	'Institutional racism is the reality.'	Stigma and discrimination – institutional racism a reality.
MD0326	Diagnosis – multiple disorders – which are attributable to alcohol? ARND subject to 'considerable cynicism.' survey of health professionals – most do not know how to make a diagnosis...if able to, lack certainty as to how to care for patients including referral for further assessment...no specific treatment. concerned diagnosis	Medical – cynicism, most do not know how to make a diagnosis, lack certainty re care and management, no specific treatment Diagnosis - multiple disorders, differential
RS0327	No national organisation to influence agenda at highest level.	Advocacy – no national peak body
AP0328	FASD not recognised as disability. Disability status dependent on IQ – very little to do with FASD. Other diagnoses sought to meet child's needs. Service delivery reactive rather than proactive.	Diagnosis – not recognised as a disability, alternative diagnoses accepted so needs can be met. Systems and service provision - reactive
SP0329	after all this time, the same position– don't tell women that alcohol is a teratogen – it will promote guilt if their child is harmed. Personal wrangling based on different belief systems - wasted over 30 years.	Denial – don't tell women alcohol is a risk Systems and service provision – personal wrangling has wasted time
RS0330	Power in language use re alcohol – people distance themselves from risk – use terms such as abuse, misuse, it is a way in which we can say 'well I'm not like that, I don't abuse alcohol, so I'm okay'. Low dose – risk issue...what advice can be given? If this was any other drug, what would our advice be? We wouldn't have the debate. NHMRC guidelines – sensible. But, risk increases at increasing levels of consumption	Alcohol – power in language use enables distancing from harms, low dose risk, guidelines sensible, assumption that public is aware, regarded with complacency, problem not mine, Women – unplanned pregnancy, young women do not heed advice as have no plan to be pregnant

	<p>if people do drink.’ Perhaps many of the heaviest drinkers are unaware of the risk and might be at increased risk for unplanned pregnancy. Young women may be given advice re alcohol use in pregnancy but claim advice irrelevant as they have no plan to be pregnant.</p> <p>Alcohol – regarded with general complacency – self-serving optimism – risk for individual not a risk for community – their problem not mine - failure to recognise subtle harms from fetal alcohol exposure. Need to understand the critical role increased alcohol consumption can have on FASD – prevalence.</p> <p>Challenge is how rationalised – if we ask someone what a risky drinker is, or a heavy drinker, you can expect it will always be someone who drinks more than them</p> <p>Subjective expectations influence willingness to intervene – e.g. the work of Margaret Cooke who did some research on the willingness of midwives to intervene in smoking. She found two main influences (1) whether the midwife smoked; and (2) what their manager thought about the relevance or importance of intervening.</p> <p>People work independently across different areas of alcohol harms and the reality is that if we drink more, there is increased harm in all areas.</p> <p>Few GPs adopt brief intervention - dearth of evidence about effective interventions but like brief interventions, the practice may work well in research study but might not be utilised in clinical settings</p>	<p>Medical profession – few use brief interventions</p> <p>Systems and service provision – willingness to intervene linked with personal use of alcohol</p>
RS0331	<p>Reluctance – hope the problem goes away – perhaps kids get picked up in the system anyway. Don’t want another major issue to deal with. Problem too hard even though cannot demonstrate seriousness of FASD problem - low rates recorded, science not solid</p> <p>Parents unable to advocate for their children like parents of autism affected children are</p> <p>Diagnosis – problematic - characteristics not observable, no biomarkers, complete spectrum minimised –ADHD going up – no biomarkers either but identified and treated</p> <p>How do they make policy priorities?</p>	<p>Diagnosis – problematic, no biomarkers</p> <p>Research – science not solid</p> <p>Prevalence – low rates recorded</p> <p>Government – not another major issue to deal with, problem too hard</p> <p>Systems and service provision – reluctance, hope problem goes away</p>

AP0332	<p>use (including health professionals) and drinking guidelines which minimise fetal risk.</p> <p>Industry – wine has health benefits, labelling absent. Regarded by elite as ‘sacred cow’ – economy, cultural/social importance.</p> <p>failure to capture FASD as one of many alcohol related harms, problem in Australia as large as Nth America, only address FAS – connected with high risk alcohol use, no evidence here so no problem here, Aboriginal problem – take responsibility for it,</p> <p>Focus on illicit drugs – bias that this is more harmful</p> <p>Lack of political will.</p> <p>failure to recognise significance of FASD or importance of correct diagnosis.</p> <p>stigma – on family determined to be a worse outcome than the disability.</p> <p>Diagnosis – a spectrum, not just FAS; acceptance of ADHD/autism diagnoses as there are no implication on mother’s lifestyles.</p> <p>Denial – too late once child born to change situation.</p> <p>Incomplete information to pregnant women.</p> <p>Women not asked about alcohol use at antenatal appointments.</p> <p>Medical profession – shield women from possibility they have harmed their baby</p> <p>Not a registered disability</p>	<p>Alcohol – focus on illicit drugs</p> <p>Alcohol industry – health benefits promoted, no labelling, sacred cow – economy, cultural/social importance</p> <p>Aboriginal – a problem for this population, so take responsibility</p> <p>Medical profession – only address FAS, not complete spectrum, importance of correct diagnosis, stigma on family viewed as worse outcome than disability, incomplete information for women, not asked about alcohol use, shield women from possible harm of child</p> <p>Diagnosis – other diagnoses have no implication for mother lifestyle</p> <p>Denial – too late once child born</p> <p>Government – lack political will, need to take responsibility</p>
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Question 4: Who do you think has been most important in bringing the matter of FASD to the attention of policy makers and the public?		
Participant No. #	Interview data	Coding
BS0101	Virtually the same answer as above in #3, with the addition of: focus on and explanation of the cost effective power of prevention services versus treatment services costs; the need for multimodal approaches to prevention beyond direct clinical intervention to include community mobilization and public health models for behavioural change.	Cost Systems and service provision
MD0102	At this juncture in time, I believe that public awareness of FAS is a logical springboard for policy makers to look at FASD.	Advocacy – increasing public awareness promotes policy maker interest
RS0103	People like Ken Warren; the ICC-FASD and national media attention concerning women’s drinking have been important. Studies have been released with the intent of convincing the public that the problem is real.	Advocacy – Warren, ICC-FASD Women - media reports on drinking
CH0104	No response	
RS0105	Some individual politicians and agencies. Movies need to be made on FASD.	Advocacy – some politicians and service providers
HP0106	Primary prevention: If we learnt something from the HIV/AIDS issue response then it was that knowledge, awareness and education does not translate to prevention. Messages about don’t take the risk do not work. Secondary prevention: Obstetricians and gynaecologists need to improve screening and referral. We need to add another screening process to doctor’s repertoire. HIV/AIDS didn’t have a big lobby group but the difference between this issue and FASD is that there was no money in perpetuating the problem. CASA (Columbia University) produced a report called ‘Shovelling it up’ which was an attempt to quantify the cost of alcohol in the United States.	Medical – ob/gyn improve screening a referral Funding – financial motive in perpetuating FASD
MD0107	The Center for Disease Control is the primary driver and is better funded to undertake surveillance. We need to know what will make a difference. We need to be ‘at the same table’. Louise Floyd CDC (National Center for Child Birth Defects) is a key person to speak to about an Interagency Agreement for Project Choices to be piloted (implemented and evaluated) in Indian country. The project is about teaching practitioners brief intervention skills using Project Choices resources and aims to assess risk and work with women to reduce alcohol use and/or educate on birth control as an option. The latter component is Louise’s focus.	Collaboration – all, interagency agreement, CDC

RS0108	<p>I don't think this has been well done. The number of cases identified is less than 2% of the 1% population prevalence rate. We have no studies of FASD rates in prisons, substance abuse treatment programs etc. The change in the number of women with problem drinking has changed very little and may have increased. Prevention programs have tended to focus on easy to access women rather than the population of women who have had children with an FASD. I have attached a copy of the relevant data from North Dakota as an example of what might be useful.</p> <p>The cost of care the difficulty of treating the core issues of FASD. The cost of care is huge and mostly preventable. In addition, much of the money spent on care is so poorly focused that it results in very limited improvement in the essential impairments in FASD. It needs to be constantly stated that the diagnostic criteria do not focus in a meaningful way and are not connected to issues that need intervention or treatment for the individual with an FASD, their family or to the systems of care. This disconnect is a key in the current funding issues, the need for services and what these services should be. For example, most of the funding spent of FASD is treatment of current issues and almost none is spent on prevention of future problems that define the severity of the disorder for adolescents and adults. Again, the facial features are not much of an issue in effective treatment or prevention of future problems e.g., mental health disorders, substance abuse disorders, entry into corrections systems or failure to achieve independent living. Facial features predict nothing in terms of effective treatment or prevention – mental health, substance use, corrective services or independent living. No studies of prevalence in prisons, substance use programs. Women's use of alcohol may have increased. Focus on easy to access women rather than those with FASD affected child</p>	<p>Demand for problem attention – not well done</p> <p>Cost – care is huge and investment poorly focused, not accounting for transitions</p> <p>Diagnosis – less than 2% of a 1% prevalence rate have been identified, criteria not meaningful, not connected to intervention, facial features predict nothing</p> <p>Research - no studies of prevalence in prison, substance use Women - research focus on easy to access women rather than those with FASD child</p> <p>Alcohol – women's use may have increased</p>
BP0109	<p>In the US, it's NOFAS-we do educate federal policy makers, and have state affiliates that we train to advocate to state legislators. NOFAS has written most of the language that has resulted in government agencies (NIH-NIAAA, SAMHSA, CDC, HRSA) receiving FASD funding.</p> <p>The former Senator Tom Daschle (D-SD) was responsible for the first FASD Bill, and was a founder of NOFAS.</p>	<p>Advocacy – NOFAS educate policy makers, state legislators, provide language to FASD funded agencies, Daschle</p>
RS0110	No response	
NG0111	Scientists who can make the problem tangible to lawmakers. Scientists who have a	Advocacy – scientist make problem tangible to

	<p>deep commitment to interact with people in all situations on all facets of the issue. People like Larry Burd and Ed Riley. These people understand the caps and can't just be scientists.</p> <p>Real people and real stories are critical.</p> <p>Michael Dorris; the NOFAS organisation; Senator Tom Daschle, a founding member of NOFAS from South Dakota (Sioux people from South Dakota were experiencing 25% prevalence rates); federal agencies; and the FASD Centre of Excellence.</p>	legislators (list of names)
ET0112	<p>The 'who' in this case is collective, much like what appears to have happened in recent events in Egypt where every single person toppled a dictatorship of thirty years' standing. No one person, but the collective 'Who' has contributed to the work toward the 'tipping effect' of change. Social networking at its best. In this field it includes everyone who simply refuses to sit down and continues to talk. These numbers include people who are doing work in very different ways, all of which has congruent goals of increasing understanding and contributing toward the goal of healing and primary prevention. That includes those working toward primary, secondary and tertiary prevention, policy makers, parents at IEP meetings, parent/professionals who are working to develop and prove effective techniques to demystify and reduce reactivity associated with FASD and addictions and all others who continue to name and educate around FASD.</p> <p>The who also includes people with stories of hope and help, which engages rather than alienates. This includes informed birth, adoptive and foster parents and professionals who together are working to develop this issue. This is slightly different from other conditions such as ADD/ADHD, ASD and others, that are primarily parent-driven. The growing FASD group is well-informed and remarkably diverse, and includes professionals who also appreciate the importance of recognition which, of course, is a required step before prevention.</p>	Advocacy – not one person, all who refused to be silent, people working in different ways but with congruent goals, not parent driven
AP0213	I would have to say, based on 35 years of doing this, that the two biggest things have been that articulate telling of human stories and birth and adoptive families working together with respect, caring and compassion and the absence of blame, shame, stigma or judgment from both sides.	<p>Advocacy – telling human stories</p> <p>Collaboration – birth and adoptive families working together with care and compassion and the absence of blame, shame, stigma or judgment from both sides.</p>
RS0214	I believe that medical and social science researchers have most reliably brought this	Research - medical and social science –

	<p>information to the attention of policy makers and the public. Media coverage is often inflammatory and unreliable on the topic of FASD. The FASD Conferences held by UBC have been very instrumental in drawing people from around the world to consider this issue in an enlightened fashion. Medical science researchers have shared their knowledge through venues such as these conferences and over time, the domination of medical knowledge has given way to more inclusiveness of social science research and this is critical in moving the agenda forward.</p> <p>I also believe the Institute of Health Economics Consensus Conference on FASD in Edmonton, Alberta, 2009 was a crucial event in terms of identifying the need for consistent approaches to policy that consider the lifespan of the individual with FASD.</p>	<p>information, international conference presentations including Institute of Health Economics Consensus Conference</p> <p>Media – unreliable</p> <p>Medical – domination has given way to more inclusiveness of social science research to move agenda forward</p>
GP0215	It has been a combination of politicians, civil servants and community members that have brought this to the attention of policy makers and the public.	Advocacy - combination of politicians, civil servants and community members
AP0216	The BC FAS Resource Society got awareness into government and lobbied for a government consultant. Carol Legge was instrumental. She wrote the first report on FAS and consulted with all communities from across BC. She set up the BC Consultation Group. And Carol went after government politicians; adoptive families; and professionals and government organizations. Carol wrote the first strategic plan for BC (which is reviewed annually). ‘You can’t just write a policy, the issue is too complicated, you need to work in the field and try to reduce the harms.’	<p>Advocacy - BC FAS Resource Society, Carol Legge.</p> <p>You can’t just write a policy, the issue is too complicated, you need to work in the field and try to reduce the harms.</p>
RS0217	In Canada, I think the most influential are the middle level bureaucrats, people like Anne Fuller and Holly McKay. Anne organises strategic planning and initiatives like the FASD Research Network. Holly is a federal government worker with the Public Health Association of Canada and has been instrumental in securing funding for ‘helpful’ projects.	Advocacy - middle level bureaucrats, people like Anne Fuller (FASD Research Network) and Holly McKay (PHAA)
SP0218	The three women I mentioned in question 2 and also the Child welfare system in BC. The FASD Nat that I am a member of has also been instrumental in educating the government/policy makers as well as others. The most effective teachers are the women who struggle with substance use during pregnancy and their children.	Advocacy - Dr Chris Locke, Dr. Liz Whynott and Nancy Poole and child welfare system, NAT, women who struggle with addiction in pregnancy and their children
LP0219	A strange crew of individuals...from Diane Malbin, Dr Asante, Juli Conry, Anne Streissguth, Sterling Clarren, Kay Kelly Edriley...etc...Despite govt money the momentum is small...doctors refuse to take a stand...just like they refused to stand up to cigarette companies in the 1960 70 80’s	<p>Advocacy – list of names</p> <p>Medical – doctors refuse to take a stand</p>

BP0220	Parent activists. FASlink Fetal Alcohol Disorders Society serves more than 400,000 people annually, online. The FASlink Discussion Forum have more than 700 members online at any time, including families, professionals, agencies, and surreptitious monitoring by the beverage alcohol industry. Publicly funded agencies only deal with FASD as long as they get funding specifically for FASD. None of the money reaches the grassroots where the real work is done. In 20 years. FASlink has received no money from governments and refuses to accept funding from the beverage alcohol industry.	Advocacy – parent activists, FASlink
ET0221	The most important thing is to provide them with the potential or correlated numbers of the incidence of FASD in children, youth and adults within their community. Identifying that the adoptive population is at extremely high risk for prenatal exposures.	Prevalence – numbers, across lifespan, adoptive populations
SP0222	Well, I would like to say that it is families like the movement for autism; but it is not - it has been front line service providers and community leaders	Advocacy – not families, it has been front line service providers and community leaders
BP0323	Us - people like Sue Miers. The Telethon Institute have a great deal of respect and credibility and they are doing research which is great but since 1998 what were these other organisations doing? In reality ‘one little person jumped up and down’ and that started the snowball People do not want to see the negatives of drinking and the alcohol industry is subversive No specific services for people affected by FASD, people have to independently find information on FASD, poor communication in service delivery Finding safe lower limit of alcohol is a ridiculous waste of money...results confound people	Advocacy – Miers, (jumped up and down) Russell, Telethon
RS0324	Dedicated carers/birth parents/human service workers have driven awareness of FASD supported by a small group of professional doctors like Sterling Clarren, Ed Riley, John Whitehall, etc. The latter have provided the evidence which groups have then built into resources for distribution to the grassroots campaigners. This chain of command continues to exhaust themselves while those at the top of the food chain sit back, ponder, procrastinate and deny.	Advocacy – parents and carers, human services workers Research – international – the evidence those at the top of the food chain sit back, ponder, procrastinate and deny.
BP0325	Elizabeth Elliott; Carol Bower; and Sue Miers. The NOFASARD history reveals little change until Elizabeth Elliott entered the arena. Elizabeth and Carol bring a level of influence to government because of their professions. Professionals can be supportive but also speed ahead and cannot wait for communities to be on board. I think the	Advocacy –Miers Medical – Elliott and Bower most influential Research - can speed ahead and leave communities aside e.g. Cherbourg Qld

	Fitzroy Crossing community were ready but this was not the case in Cherbourg.	
MD0326	<p>The formation of the Intergovernmental Committee on FASD Working Party as an outcome of the Ministerial Council for the Drug Strategy was very important - brought together clinicians; researchers; policy makers; big alcohol research institutes and government representatives (state and federal). Identified the major issues surrounding FASD in Australia and a Monograph was written - a range of recommendations, which we were asked to prioritise: investigating the prevalence of FASD in high risk communities; education of professionals in health, education and justice; development of screening and diagnostic criteria for Australia; development of services; funding for research; and development and dissemination of evidence-based policy and 5 or 6 recommendations from the Monograph have been taken up.</p> <p>In 2010 our group (The University of Sydney Medical School, The George Institute for Global Health, Nindilingarri Cultural Health Services, and Marninwarntikura Women's Resource Centre) received \$1.5 million from the Department of Health and Ageing (DoHA) and FACSIA to work in the Fitzroy Valley in WA to conduct a prevalence study for FASD. This project was highlighted in the 2010 Social Justice Report published by the Australian Human Rights Commission.</p> <p>The DoHA has also established a group called the FASD Data Collections in Australia to determine what data about FASD should be routinely collected. Additional funding (\$500,000) was obtained by our group to determine consensus regarding appropriate screening and diagnostic tools for FASD for use in Australia.</p> <p>The National FASD Resources Project has also been established to determine what data should be routinely collected on alcohol use during pregnancy. I have also been invited to give numerous presentations about FASD to medical and lay groups. This included a presentation to the Prime Minister's Science Engineering and Innovation Council (PMSIEC), which reports directly to the Prime Minister and Health Minister.</p> <p>The other important factor has been Australian and New Zealand attendance and participation in international conferences.</p>	Collaboration – IGC-FASD, research group Fitzroy Valley, FASD Data Collections, FASD Resource project, international conferences
RS0327	Again, I would credit Sue Miers with being most important in bringing the matter of FASD to the attention of policy makers and the public. I also think the work of researchers, for example Elizabeth Elliott and Carol Bower have influenced policy.	<p>Advocacy – Sue Miers for attention to policy makers and public.</p> <p>Research – researchers Elliott and Bower influenced policy</p>

AP0328	People like Vicki Russell	Advocacy – people like v Russell
SP0329	Sue Miers – her eyes were opened to the problem with her adopted daughter. Maybe the position has changed now for Elizabeth Elliott, I am not involved that much anymore.	Advocacy – Sue Miers, maybe now E. Elliott
RS0330	Better detection and training in medical and nursing schools - FASD is better incorporated in clinical knowledge and therefore more at the front of clinical care and management. Better technology allows better understanding of the more subtle forms of FASD and the awareness that it is more widely spread than perhaps we thought. The role of various advocacy groups raising awareness and community leaders in some Indigenous communities raising the profile of the problem.	
RS0331	Those who stuck with it. Movement is happening and this has meant more and more people have come on board. This makes us stronger as a group and we have loosely stayed together; not fractured.	Advocacy – those who stuck with it, more joined, made stronger, stayed together, not fractured
AP0332	NOFASARD; Telethon Institute Child Health Research; Prof Elizabeth Elliott; DEN; Aboriginal Drug & Alcohol Council (SA); RFFADA; Salvation Army; Women's Christian Temperance Union; Fitzroy Crossing Women; Arbias; IGCD; Rural Health Education Foundation; FARE	Advocacy – list of names

Question 5: Is there a person or entity you can think of whose support for the prevention of FASD will be essential in the future?		
Participant No.#	Interview data	Coding
BS0101	Pervasive acceptance of alcohol, address the impact in families and especially expectant mothers, tribes and culture must address prevention and acceptance of alcohol	Aboriginal – tribes must address prevention
MD0102	Industry on board	Alcohol industry – on board
RS0103	Major institutions - NIAAA-public health, SAMHSA AND HRSA – ways to work with people. Boots on the ground ‘to sustain change’ with no one entity/source	
CH0104	No answer	
RS0105	Bills in Congress. ‘Autism is darlings’ disease’	Government – Bills in Congress. Autism more acceptable.
HP0106	No response	
MD0107	<p>Tribal readiness and community readiness</p> <p>Motivational interviewing</p> <p>Tribal entities willingness to take this on in all 564 sites.</p> <p>National Resource Centres have the human resources but we need to consider women’s rights, their equity in the subject of alcohol abuse and alcohol exposed pregnancies. We also need to consider the intergenerational impact of all traumas and the infant affected by prenatal alcohol exposure. How do we break the cycle?</p> <p>University research and especially applied research.</p> <p>The stigma could be changed. The name FASD is a barrier in itself. FASD only describes the initial insult and we have probably not done a good service in the ‘social marketing done to ourselves through the name.</p>	<p>Aboriginal – need to be ready, willingness to take on, intergenerational impact of trauma and how to break the cycle</p> <p>Medical – motivational interviewing increased</p> <p>Women – service providers need to consider women’s rights, equity</p> <p>Research – university based and applied</p> <p>Stigma and discrimination – name FASD a barrier</p> <p>Diagnosis – name only describes initial insult</p>
RS0108	We need to spend a good deal of time learning how to educate legislators, administrators of maternal and child health programs, foster care programs, paediatricians etc. The decisions from this group will be essential if we are to get them to route funding from (take away) other programs and to use the money for FASD. It is clear that we are losing funds to obesity, diabetes, autism etc. and we need to learn how to take money from them for FASD. The idea that we will only be able to access new funds is not useful. We need to be able to increase our share of funds from the existing pool of funds. This is a crucial point that is often lost on people applying for funding who often have a naive approach that they will be able to access uncommitted funds. This is very	<p>Systems and service providers – administrators need education – maternal/child health, foster care, paediatricians; this group will then support lobbying at government level</p> <p>Funding – losing funds to other conditions, no new funds available and this needs to be understood by those applying</p>

	difficult and we need to compete for existing funds.	
BP0109	US Sec. of Health & Human Services, US Surgeon General	Government – Sec Health & Human Services, US Surgeon General
RS0110	No response	
NG0111	Individuals and families affected and willing to talk, NOFAS, Media	Advocacy – individuals/families, NOFAS, media
ET0112	Collective entity of informed individuals. Work value undefined by professional role of status	Collective of informed individuals
AP0213	Persons in positions of influence, parents – birth and adoptive in media who need to tell their stories like with AIDS	Advocacy – persons in positions of influence, parents
RS0214	I believe Canada has been very instrumental through the Canada Northwest FASD Partnership and Research Network to consistently bring this issue forward to the government, to professionals through conferences and the Network Action Teams. I believe the NAT on Women's Health led by Nancy Poole and Amy Salmon in collaboration with team members is a very critical entity in developing prevention knowledge.	Advocacy – Can NW Partnership, Research Network – NAT on women's health
GP0215	Continued support of senior bureaucrats and provincial politicians, collaboration - cross-ministry committee on FASD	Government – senior bureaucrats, politicians, cross-ministry
AP0216	Dr K. O. Asante has characteristics of respectfulness, he is non-judgmental, gentle. He is experienced and assertive. He was born in Ghana so he understands community and first nation cultures. Dr Conry is a registered psychologist who specializes in criminal justice. She has been an A/Professor at UBC and her knowledge of the brain and assessment domains is critical. She identified the 'red flags' for FASD and developed the Probation Assessment Screening Tool. She is both an educator and a researcher. The third person is me. I bring into the team, the influence of a family member who is recognized as part of a team that is without hierarchy. The team has now been working together for 10 years and flexibility is important to sustaining the team. The Asante Centre now has 5 doctors, 3 psychologists and two speech /language therapists. Students come here to do their practicum. Nancy Poole is probably the new Carol Legge. She has introduced women's addictions into the field. <i>Question: What about birth mothers? Has this group been important? YWCA Crabtree Corner raised awareness about the experience/s of birth mothers.</i>	Systems and service provision – include parents as team members Medical – respectful doctors, knowledge of brain Women – women's addiction specialists, birth mothers
RS0217	Many people in the circle	Many
SP0218	Dependent on government decision makers. Network influences policy makers	Government – decision makers Research – outcomes influence policy

		makers
LP0219	Whole community	Many
BP0220	Prevention will only happen if there is political will and the appropriate funding. It costs \$85,000/year to incarcerate a prisoner, more than half of whom have been shown to have FASD. We are imprisoning people because they were born with neurological disabilities. Yet we won't provide the early diagnosis and intensive intervention funding that could have far better outcomes. We won't provide supports for families trying desperately to deal with FASD. We don't provide adequate income supports for those who cannot work or manage money to support themselves. We force aboriginal communities to live in abject poverty, without clean water, healthy food, education and the basic infrastructure demanded by non-native communities. Those things for First nations communities are the responsibility of the federal government and their funding is nowhere close to that provided by our provincial governments to non-native communities. It is scandalous. It costs \$85,000 annually to incarcerate an adult; \$120,000 to incarcerate a juvenile. Ontario Disability Support Program payments are a maximum of \$1,050/month or \$12,600/year. 'Statistics Canada defines the 'poverty line' (or low-income cut off) for a single person living in a major city in 2007 as \$21,666 (before ta-).' Only political will can change this.	Government - political will, appropriate funding Aboriginal- forced into abject poverty
ET0221	Interventions	Systems and service provision - interventions
SP0222	No response	
BP0323	No response	
RS0324	AMA and specialty organisations commitment to educating memberships – only accept education from their own profession 'such is the exclusivity' FASD included in all medical training Enough doctors to do the educating in practice Shift the mindset on ADHD, autism etc 'medical lobby is too powerful'	Medical – is powerful, AMA and professional organisations are 'exclusive' and educate their own memberships Workforce training – medical schools Diagnosis – shift the ADHD-autism mindset
BP0325	Component to women's treatment facility, Can NW FASD Research Network – leadership role Specialising in services for pregnant women	Systems and service provision – women's treatment specific
MD0326	government may not be investing in the most appropriate way so funds are not effective need government support and public funding adds credibility	Government – more effective use of funding
RS0327	A national organisation to keep prevention on the agenda at highest level A partnership to provide a national platform for parents, professionals, 'and experts' in the FASD	Advocacy – national organisation to keep prevention on policy agenda; develop a

	<p>field. A partnership to identify emerging and unmet issues and how these can be addressed</p> <p>A partnership to develop a national strategic multi-sectoral approach and contribute to National Drug Strategy for inclusion of FASD</p> <p>Gain support from PHAA and other professional organisations and colleges</p> <p>A proposal for funding research, evaluation of programs</p>	<p>national strategic multi-sectoral approach, engage PHAA and other professional organisations</p> <p>Collaboration - a national platform for parents, professionals, 'and experts' in the FASD field; identify emerging and unmet issues and how these can be addressed</p> <p>Funding – research and evaluation</p>
AP0328	Specialists and school teachers/support staff who are not afraid to have conversations with parents.	Systems and service provision – no fear in talking with parents
SP0329	The media is powerful and the messages need to be often repeated. This seems to have worked with alcohol and driving. It's about public education.	Media – repeated messages
RS0330	<p>'we might have criticism of the hegemony of medicine, senior obstetricians, midwives and groups like the AMA and other mainstream health groups are critical'</p> <p>Less criticism for those in the alcohol field who raise the issue</p>	<p>Medical – hegemony but senior obstetricians, midwives and groups like the AMA and other mainstream health groups are critical'</p> <p>Systems and service provision – less criticism of those in alcohol field who raise the issue</p>
RS0331	<p>Government is key for resources, leadership instead of dragging feet in some jurisdictions</p> <p>Evidence</p> <p>Service providers who can diagnose and offer supports</p> <p>Perception still exists that women will be blamed and kids can't be helped</p>	<p>Government – resources, leadership instead of hesitancy in some jurisdictions</p> <p>Research – evidence base</p> <p>Medical/allied health – who can diagnose and offer support</p> <p>Stigma/discrimination – must be overcome</p>
AP0332	Medical professionals all levels	Medical – profession – all levels

Question 6: Conversely, is there a person or entity whose opposition would seemingly be almost impossible to overcome?		
Participant No.#	Interview data	Coding
BS0101	pervasive acceptance of alcohol address the impact in families and especially expectant mothers tribes and culture must address prevention and acceptance of alcohol	Alcohol – pervasive acceptance, cultural context to prevention Systems and service provision – address impact in families Women – pregnancy
MD0102	the alcohol beverage industry	Alcohol industry
RS0103	Congress stopping funding	Government – cease funding
CH0104	No response	
RS0105	Nothing off hand - a tension between government legislation and personal behaviour.	Government – policy position re legislation v personal behaviour
HP0106	No response	
MD0107	Alcohol lobby and social/economic set up values alcohol – a cultural norm, a highly profitable commodity There is a native cultural [drinking] norm which is a different cultural norm.'	Alcohol industry – lobby Alcohol – social/economic value, cultural norm and profitable commodity Aboriginal – native cultural norm which is different
RS0108	Government funds next year what was funded last year need to access existing funds Key issue - legislators don't understand how much current service delivery and funding is already related to FASD Need to fund substance abuse treatment programs Early identification of alcohol uses in women and prenatal alcohol use	Government – repeatedly funds same programs, lack appreciation of funds spent to current projects which absorb FASD, need funding for treatment programs Systems and service provision – a share of existing funds
BP0109	Medical field	Medical – the profession
RS0110	No response	
NG0111	Opposition from birth parents; Federal/State Agencies; Lawmakers and other policymakers; Professional Organizations; and the alcohol industry.	Parents Government – agencies, legislators, policy makers

		Systems and service provision – professional organisations Alcohol industry
ET0112	Economic power and influence of liquor industry. Not keen to acknowledge social problems associated with products or influence sales and profits Government – formidable – ‘tremendous income’ from ta- What would increase awareness of FASD and threat of reduced sales mean in terms of engagement in prevention? reallocation of resources to prevention would offset lost revenue Those in actual or perceived positions of power or with power granted by others	Alcohol industry – economic power and influence Government – formidable - income from alcohol ta- What would increase awareness of FASD and threat of reduced sales mean in terms of engagement in prevention? Those in actual or perceived positions of power or with power granted by others
AP0213	Various families stand together as it is not a white issue. ‘Ourselves. Not even the alcohol industry would be a barrier’	Advocacy – ourselves
RS0214	Ongoing will to bridge the gap between medical approach and social science approach Cooperation between medical approach and social science approach and there is a will to bridge these gaps lack of single system to work with a family across the lifespan – a new model is needed – transition from childhood to adult services the problem of IQ measurement for functioning ‘is inadequate and flawed’	Medical – versus social science approach Future – a willingness to bridge the gap between medical and social science approaches Systems and service provision – a new single model is needed, transition from childhood to adult services and assessment not reliant on IQ
GP0215	some support from the alcohol industry for a number of prevention activities others have not created barriers	Alcohol industry – some support for prevention activities but also creates barriers
AP0216	thinking locks women into harmful place Federal government and conservative politics and traditional mindset FASD the one injustice in society and child pays the price. FASD crosses all systems of government addictions field – message is stop drinking and client responsibility – no drugs and give over to a higher power	Women – thinking that locks women into a harmful place. Government – conservative and traditional mindset. Systems and service provision – FASD cross sector impact, addictions driven by abstinence value and client responsibility
RS0217	obstacle - high level decision makers – government Ministers – any one of these people could	Government – Ministers, Chretien got it.

	<p>withdraw – ‘would be demoralising’ a solid response is needed the rest of us are doing OK – at the same table and dedicated Chretien ‘got it’ he fostered a child with FAS, did a lot for Aboriginal people as an issue, FASD is ‘so tentative’ a more conservative government funds going off shore in maternal health when needed at home tendency to throw funds at problems rather than improve situation women’s health not on the table like in Australia – non government clinics and advocacy role Women’s health in Canada operated from within the medical system Centre of Excellence for Women’s Health tries to promote less profiled women’s issues</p>	<p>Conservative Women – women’s health not on the policy table as in Australia, sits in medical system [Does this effect gender not being raised as a prominent issue for Australians interviewed?]</p>
SP0218	change of government – return to judgemental, blaming and punishing practices of past	Government – judgemental, blaming and punitive values
LP0219	<p>alcohol industry politicians paid in donations by alcohol industry</p>	Alcohol industry – donates to politicians
BP0220	<p>alcohol industry influence \$3.2b taxes but alcohol causes \$50b in damages politicians don’t want public offside through decision-making massive denial</p>	<p>Alcohol industry – \$3.2b ta-es but alcohol causes \$50b in damages Government – change in policy re alcohol may impact on electorate and voting Denial - massive</p>
ET0221	a woman in severe stages of addiction	Women - addiction
SP0222	<p>most governments are short sighted 10 year strategic plans are in place with high expectations but not matched by funding if FASD not supported it will come crashing down in the future</p>	Governments – short sighted, strategic plans not matched with funding, high cost if FASD not supported
BP0323	<p>lack of funds to do what needs to be done how allocated by government in denial are paediatricians, psychiatrists high status mother to come on board – to stand up</p>	<p>Funding – lack of, how allocated Medical – denial Advocacy – high status mother stand up</p>

RS0324	alcohol industry with vested interest doctors with vested interest in alcohol industry are recalcitrant ignorance/reluctance of medical profession to advocate for unborn hinders progress most resistant are psychiatrists – untouchables psychiatry- clearly defined diagnoses – demigods or waiting for DSM	Alcohol industry – vested interest Medical – vested interest in alcohol industry, denial by resistant psychiatrists, follow clearly defined diagnostic criteria so will rely on DSM
BP0325	people with good intentions who don't understand the context of the work government departments limited funding Incorrect information from GPs	Systems and service provision – people who don't understand and government department workers Funding – limited Medical – incorrect information
MD0326	alcohol industry – opposed to taxation and labelling	Alcohol industry – opposed to taxation and labels
RS0327	none	NA
AP0328	paediatricians – don't know or understand the condition or features	Medical – ignorance and lack understanding of spectrum
SP0329	alcohol industry – no responsibility for produce and harms alcohol – no warning, no statement of teratogenic risk	Alcohol industry – no responsibility, no warning of risk
RS0330	failure to see personal relevance of FASD change the nature of the message/s and appropriate media to deliver	Failure to understand FASD has personal relevance Future – change the message to encourage
RS0331	people challenging the integrity of what is being attempted alcohol industry – countering the science the alcohol industry – opposed support for change in communities – Fitzroy Crossing, police concerned industry will prevail	Alcohol industry –challenging science as in Fitzroy Crossing
AP0332	medical profession	Medical - profession

Question 7: What, if anything, do you think keeps government interested in the prevention of FASD and doing something about the issue in your country?		
Participant No.#	Interview data	Coding
BS0101	‘a moral imperative to help...simple, but that powerful...	Systems and service provision – a moral imperative to help
MD0102	Scientists need to demonstrate the impact of FASD as an extension of public health	Research – demonstrate impact on public health
RS0103	NIAAA and CDC – more funding continual evidence on prevalence to government	Funding – national institutions
CH0104	No response	
RS0105	‘these kids are already receiving services.’ SAMHSA; CDC initiative and HRSA need more funding across the board for community education, intervention and treatment services.	Systems and service provision – children living with FASD already accessing services Funding – for national institutions to deliver education, interventions and treatment services
HP0106	No response	
MD0107	Don’t look at gender and the specific issues related to gender and how we work with women Maternal care practices are increasingly medicalized. Need comprehensive care and health promotion to match the issues challenging women and their general wellbeing consider ‘the epigenetic fetal impact and the critical need for early intervention’	Medical/health – avoid consideration of specific gender issues which must be invested in to ensure general wellbeing, maternal care practices increasingly medicalized Research - epigenetics
RS0108	Ongoing information about FASD especially the burden on service systems and the potential to decrease costs and improve outcomes	Systems and service provision – recognise burden, decrease cost and improve efficacy
BP0109	Funding	Funding
RS0110	No response	

G0111	<p>'NOFAS and other organization advocate ... at the federal level. This legislative advocacy needs to increase, but it's been just consistent and visible enough to preserve the approximately \$25 million annually appropriated for FASD.'</p> <p>Key federal employees have also kept FASD research and public health relevant; organizations who advocate at fed level</p> <p>NIAAA, CDC & NOFAS and other organizations advocate at the federal level. This legislative advocacy needs to increase.</p> <p>Recognition on FASD as a health concern despite lack of reliable incidence/prevalence evidence.</p> <p>'Government supported research did provide the basis for the 1981 and 2005 United States Surgeon General advisories regarding alcohol use during pregnancy and the 1989 law requiring an alcohol during pregnancy warning label on all alcohol containers sold in the United States'</p>	<p>Advocacy – NGO's and national institutions at legislative level</p> <p>Research – researchers keep FASD as a public health issue, lack reliable evidence but recognise FASD as health issue</p>
ET0112	<p>Sustained interest by government...'is a function of personal knowledge, healing, and enlightenment...fundamental human kindness, values that place human and social health above economic gain, recognition of the importance of diversity and appreciation of cross-cultural contributions, and a vision that includes healing and a healthy community and recognizes and prioritizes the steps toward realization of that vision.</p> <p>Funding</p>	<p>Government – sustained through knowledge, enlightenment and human and social health above economic gain.</p>
AP0213	No response	
RS0214	driven by economics	Cost
GP0215	the high cost and loss potential that FASD causes	Cost
AP0216	The priority is the report card on BC – poverty, parents, education. If we don't care about the basics – home and food. Olympics were more important than families. Dr Asante often remarks that our children are not important enough.	Government – do not prioritise children
RS0217	No response	
SP0218	<p>Government is influenced by research and how much money they would save by preventing the syndrome.</p> <p>A great deal of research being done worldwide on the brain and different disorders including the effects of cortisol on the developing fetus-cortisol is the hormone secreted in higher quantities when the body is under stress- the women who I work with have high stress levels.</p>	<p>Government – research and cost saving through prevention</p> <p>Research – brain and cortisol secreted during stress (women)</p>

LP0219	Government knows FASD has high costs FASD has no federal support...and it has much provincial support Federal governments pay for more than 2 years in jail...provinces pay for up to two years so there is a funding tension FASD challenges a core belief.....I would not do that so you should go to jail’.	Government – awareness of high cost, no federal support but has provincial support Values/beliefs – FASD challenges core
BP0220	Parents and other activists have to continually push and prod and keep the issues before politicians and bureaucrats. Change happens when political careers are threatened Funding	Advocacy – parents and others push FASD at political and systems level Government – change when careers are threatened. Funding
ET0221	Cost to government for persons of disability, fear of being sued like with government adoption agencies	Government – FASD cost
SP0222	Need to empower families to come forward and become more engaged and public about their needs - birth families. Foster families seem self-serving when they take on this role. Adopted parents can be powerful but this can discourage birth families from involvement. Governments around the world still believe that this is a small problem. Until they understand the depth of the problem they will likely have superficial engagement. Future cost savings but because B/C governments are short sighted (from one election to the next) we likely will have little impact on this. Diagnostic capacity will provide evidence of prevalence.	Advocacy – empower birth families to speak out, foster and adoptive families can seem self-serving or discourage birth families Governments – minimise the problem and superficially engage., shortsighted, one election to the next. Diagnosis – capacity will provide evidence of prevalence.
BP0323	Government not interested enough quite yet, not proactive – want to keep a lid on the problem Education system not interested to run education programs in schools, most is offered from non-government sector.	Government – not interested enough, minimise the problem Systems and service provision – education system not interested in educating, more offered by NGOs

RS0324	<p>Governments hamstrung by medical profession</p> <p>Government frustrated by lack of interest from medical profession</p> <p>Politicians appear to be hamstrung by doctors ... in relation to changing health policies and health costs.</p> <p>The most obvious cost to the nation is the abysmally low literacy achievements of some population groups which is then a pathway to involvement with the juvenile justice system and then adult incarceration.</p> <p>The mental health problems along that pathway are not identified because those with FASD are reliant on diagnosis which of course does not happen.</p>	<p>Medical – hamstrung government, frustrate government through lack of interest</p>
BP0325	<p>more research</p> <p>the diagnosis</p> <p>no diagnostic coding for FAS. Needs to be led by groups like AMA</p>	<p>Research – need more</p> <p>Diagnosis – no coding for FAS</p> <p>Medical – AMA need to lobby for recognition as disability</p>
MD0326	<p>The need to provide support for disability and recognition that assessment and early intervention is important.</p> <p>Alcohol is a major social problem in Australia - basics preventative measures - warning labels, educations and alcohol restrictions, e.g. restricting the sale of full-strength or take-away alcohol from certain outlets or legislating certain communities as ‘dry’.</p> <p>Support for communities that indicate their concern regarding alcohol problems.</p> <p>Increased prices and increased taxation on alcohol are proven effective deterrents.</p> <p>The review of the NHMRC Australian Alcohol Guidelines in 2009 - pregnant women and women considering pregnancy advised ‘the safest option is not to drink alcohol’.</p> <p>Government interest because of costs of alcohol misuse is crucial.</p> <p>Alcohol avoidance needs to be included amidst a range of preventative health measures that contribute to a ‘healthy pregnancy.’</p>	<p>Government – support for disability</p> <p>Alcohol – major social problem</p> <p>Government policy - warning labels, education and alcohol restrictions, support for communities that seek to be ‘dry’, a range of health measures that contribute to healthy pregnancy</p> <p>Government – interested because of cost of alcohol misuse</p>
RS0327	<p>publication of research and factual information</p> <p>high level committee participation</p> <p>advocacy in community and lobbying parliamentarians</p>	<p>Research</p> <p>Government-high level committee</p> <p>Advocacy-in community and government</p>
AP0328	<p>Is government interested?</p>	<p>Government – is government interested?</p>

SP0329	<p>The government not particularly interested?</p> <p>There is the potential for so much lost revenue.</p> <p>They will lose votes if they rock the boat.</p> <p>the power of the alcohol industry is almost stronger than the power of government.</p> <p>The problem is bigger than FASD - our next generation of parents and are drinking like never before.</p>	<p>Government – not particularly interested, risk of lost revenue and votes</p> <p>Alcohol industry – powerful than government</p> <p>Alcohol – rate of drinking higher</p>
RS0330	<p>Political support means identifying the problem and helping to identify the solutions.</p>	<p>Government – support would recognise the problem and solutions</p>
RS0331	<p>Progress is slow and government is pretty reluctant sometimes.</p> <p>Issue has not gone away and government and service providers and the broader community need to get its head out of the sand.</p> <p>[Alcohol] industry is very influential and has access to powers that challenge this progress.</p> <p>The big question about low levels of alcohol to cause harm continues</p> <p>I have heard around ‘table talk’ with experts involved that the evidence is not that strong. It is a bigger issue than FASD.</p>	<p>Government – reluctant, progress slow, head out of sand</p> <p>Alcohol industry – very influential inside government</p> <p>Alcohol – low levels to cause fetal harm continues</p> <p>Research – evidence not that strong, bigger issue than FASD</p>
AP0332	<p>Some state governments display a total lack of will</p> <p>Pressure from influential people (Professors Elliott and Bower – APSU and Stanley Telethon Institute) has promoted interest by Federal government</p>	<p>Government – lack of will, pressure from experts</p>

Question 8: What, if anything, do you think slows down or gets in the way of FASD prevention policy in your country?		
Participant No.#	Interview data	Coding
BS0101	'balancing multiple needs and limited budgets... FASD is one of many ...all vying for very limited federal funding	Government – limited budgets, competitive issues vying for attention
MD0102	No response	
RS0103	No response	
CH0104	No response	
RS0105	physicians doing a lot more to promote discussion on alcohol use during annual	Medical – could be doing more
HP0106	No response	
MD0107	The US Surgeon General statement sets a standard and yet, popular media says this is not true or discounts this or flies in the face of this statement. There are certain voices which dismiss the science and yet policy is informed by the science. A roundtable approach.	Government – some dismiss the science and yet policy informed by science Media – discounts standard – warning Collaboration – round-table
RS0108	The competition for funding is important and people in the FASD field need to improve their strategies for obtaining funding. Public education about FASD is important in improving funding. Competition for funds by other advocacy groups seeking to increase their share of existing funds. A completely different system of diagnosis, prevention and treatment if we are to be successful in improving prevalence rates and outcomes for people with FASD. Improve the inclusion of FASD relevant information in the pre-service training and in-service education for people from the relevant disciplines. A lack of systematic education of policy makers and agency administrators who tend to see FASD as someone else's problem (they are interested but usually are not willing to take money from someone else to fund FASD activities).	Funding – competitive Advocacy – improve strategies for attracting funding, understand is about sharing existing funds as no more available Medical – different system for diagnosis, prevention and treatment needed – for evidence of prevalence and longer term outcomes for people Systems and service provision – pre-service training and in-service education across disciplines Government – systematic education for policy makers and administrators
BP0109	scientific evidence (or lack of) on moderate drinking.	Research – evidence on risk of moderate drinking
RS0110	No response	
NG0111	stigmatise FASD individual most undiagnosed/misdiagnosed	Stigma and discrimination – individual and birth mother

	<p>lack of uniform diagnostic criteria diagnosis and guidelines for ARND</p> <p>the exclusion of FASD in the diagnostic and statistical manual of mental health disorders</p> <p>stronger incentive based leadership</p> <p>a lack of FASD incidence and prevalence data</p> <p>lack of co-ordination</p> <p>stakeholders willing to advocate has not reached critical mass</p> <p>families meeting own needs means time for advocacy minimised, No effective parent groups over long periods of time for FASD.</p> <p>a lack of public and private resources</p> <p>federal, state and local government deficits</p> <p>stigmatise of birth mother</p>	<p>Diagnosis - most missed, lack of uniform criteria and guidelines</p> <p>Medical – FASD in DSM</p> <p>Leadership – incentive based, lack of co-ordination</p> <p>Advocacy – not reached critical mass, families pre-occupied in meeting own needs, no effective parent groups</p> <p>Funding – lack of private/public resources</p> <p>Research – lack of incidence and prevalence data</p> <p>Funding – government deficits</p>
ET0112	<p>Values structure which fails to prioritize human need, or recognize health as essential for a viable civilization, superficially and reactively rather than proactively</p> <p>Preventively defines problems and solutions, and prioritizes short-term economic gain over long-term social health.</p>	<p>Values – fail to prioritise need, health, reactive, short term gain over long term social health</p>
AP0213	<p>Once there was equality, now is somewhat divided - how we value ourselves</p> <p>Once funding is made available, organisations jump on the bandwagon to offer programs</p> <p>Academic versus parent and there is no conversation</p> <p>The 100% preventable message might have been a mistake. Perhaps it asked too much of some women.</p> <p>There is a lack of recognition of the disability. Are some of us disposable?</p> <p>FAS has been called ‘the orphan group of disability.’</p> <p>Another parent advised delegates at a conference ‘You see the snapshot, we see the moving picture.’</p> <p>‘Donna Debolt said it was a pity this group ‘spoke as well as they think.’ [She is describing the fact that FASD does not always present to the unaware, as a set of disabilities and this creates an illusion of normal functioning.]’</p>	<p>Government – lack of disability recognition, discriminatory. Orphan of disability</p> <p>Funding – dried up, competitive</p> <p>Academic v parent</p> <p>Women - prevention message may have asked too much of some women</p> <p>You see the snapshot, we see the moving picture.</p>
RS0214	<p>Systems that support children are evolving, mostly through the work of physicians, social workers and psychologists on an individual/case by case basis. An overall applied model does not exist and responses vary dependent upon the individual who receives the case.</p> <p>A lot of good work is being done by committed individuals who have taken a strong</p>	<p>Systems and service provision – evolving, overall approach lacking, response dependent on worker, some good work happening, in-service training for justice and work with</p>

	<p>interest in providing good care to individuals/families and systems such as child welfare who respond to this issue.</p> <p>Child welfare policy could become more highly developed and identify protocols for working with these complex/high risk families.</p> <p>PCAP is very effective and their needs to be greater collaborative work between PCAP and child welfare – usefulness could be better recognized.</p> <p>The stigma associated with FASD and professional silos and systems slows down policy development. A significant gap in training in areas such as the justice system where adults with FASD are often found and more policy development is required.</p> <p>In Canada, each province and territory has their own approach to FASD.</p>	<p>adults</p> <p>Government – jurisdictions have different approaches</p> <p>Government - develop child welfare policy to support family with protocols, work closely with PCAP</p> <p>Women – PCAP effective</p> <p>Stigma and discrimination – professional silos, slows down policy development</p>
GP0215	Cost not specific to FASD - purely economics. A downturn means prevention programs are hit.	Funding – not limited just to FASD programs
AP0216	No response	
RS0217	<p>FASD prevention is the toughest field and it's a problem based on a medical model. Once born, and the child is affected, the problem is less medical.</p> <p>But it is about how the powers that be like the medical model.</p> <p>The health care system is more powerful and recently, the BC government has introduced a home visiting program for teenage mothers by a nurse. I argue it does not need to be a nurse but nurses built the evidence base in the first place. Teenage mothers are not the biggest problem – women birthing 3rd child are at much greater risk.</p> <p>Ambivalence about women's equality versus the rights of the child</p> <p>FASD Conferences are moving towards greater focus on epigenetics for example.</p> <p>While we need to know about brain mechanisms, very few people do this work. We need to be looking at what to do with this information and research on interventions.</p> <p>The child and family need a medical diagnosis but also need a social network of paraprofessionals working with families in a respectful model of intervention.</p> <p>There is a lot of ambivalence about alcohol</p>	<p>Medical – prevention tough, medical model, once child born problem less medical</p> <p>Government – like medical model</p> <p>Systems and service provision – health care system powerful</p> <p>Women – teenage mothers not the biggest problem, women having 3rd child, equality issues re women v rights of child</p> <p>Research – increased focus on epigenetics.</p> <p>Research – brain mechanisms focus but few do this work</p> <p>Research – need attention to interventions - child and family need diagnosis plus social network to work with family</p> <p>Alcohol – ambivalence re use</p>
SP0218	No response	
LP0219	Philosophical definitions, people arguing re best prevention initiatives, FASD not understood as a preventable brain based birth defect, FASD individuals seen by conservative governments as 'unfixable criminals'	Government - FASD not understood, argue over best prevention approach, FASD linked with criminals

BP0220	Massive denial - government does not preference FASD as policy	Government – massive denial, not prioritised
ET0221	change in govt and re-education of new	Government – re-education of each new one
SP0222	Autism. The media grabbed research from the UK that it was ok to drink and not the poor standard of research. Societies desire to want to convince themselves that alcohol and drinking is ok. Aboriginal people have accepted that alcohol causes great deal of problems - our white culture has not yet accepted this, thus aboriginals get painted with this problem when in fact it is everywhere.	Government – autism easier for policy Research – media latch on to ok to drink rather than poor standard of research Alcohol – society convince drinking OK Aboriginal – cultural acceptance alcohol causes problems, not white culture, aboriginal people cast as site of issue
BP0323	Pressure and income from alcohol industry for governments Problem has hit critical mass and there are multiple issues. Consider voters and how many people drink	Government – pressure from alcohol industry when problem has hit critical mass and consider voters who drink
RS0324	Strong interest groups within the alcohol industries - do not want changes that could place responsibility or costs. Political candidates being reliant on electoral donations cannot be separated from this reality even with the health of unborn babies being at risk. No political champions politicians at the uppermost level at open forums. They agree in person but are loath to speak out. Alcohol enjoys special exemptions from food standard laws around labelling of contents. Money appears, groups get interested The likelihood of significant prevalence rates using other data, there is still no action. The publication of misleading research findings in 2010 has cast doubt on our abilities to convince the international forum that, not only do we have a problem with FASD, but that we are incapable of producing the evidence. Australia will resonate from this highly irresponsible research for years to come. It is such a sorry state of affairs that poor research makes it through incompetent peer review systems to the reader.	Alcohol industry – strong interest group, seek status quo, no responsibility or cost Government – politicians rely on electoral donations, no champions to speak out, high prevalence likely but no action Alcohol – exempt from food standards, labelling Systems and service provision – funding comes and interest is sparked Research – some misleading, poor with incompetent peer reviews
RS0325	Politics – State, National and local levels	Government – politics at all levels
MD0326	a lack of will and a lack of money for national public health programs	Government – lack political will, lack of funding for campaigns
RS0327	lack of influential national organisation	Advocacy – no national organisation
AP0328	The power of the alcohol industry, maintaining IQ as measurement of this disorder. The lack of knowledge on FASD, absence of prevention	Alcohol industry – power Diagnosis – reliance on IQ measurement

		Policy – lack knowledge, no prevention
SP0329	<p>Alcohol is so impregnated in our culture – the weekend binge; it's part of the lifestyle; it's all soaked into the culture.</p> <p>May be self-medicating to cope with an-iety and stress.</p> <p>Government is trying to reduce youth alcohol as separate from other groups – a whole of life approach is needed.</p>	<p>Alcohol – impregnated in culture, self-medication</p> <p>Government – separate population groups in policy rather than alcohol as a harm across life</p>
RS0330	<p>Until recently advocacy around alcohol has largely come from those from the alcohol/drug services. We need to garner support from a range of mainstream services – cancer Council, education groups, the AMA, parent groups and so on.</p> <p>Co-ordinate better responses to a range of alcohol problems and better communicate the critical role of alcohol's availability.</p> <p>'As alcohol becomes increasingly available there will be an increasing prevalence of drinking by many in society including young women. It doesn't matter how many brief interventions are in place, if we allow increasing alcohol consumption there will be an increase in health concerns, e.g. breast cancer. Young women are drinking like never before and this will lead to increases in a range of health concerns.'</p>	<p>Advocacy – needs cross sectoral support</p> <p>Government – policy regulate availability of alcohol, rate of alcohol use equal increase in health concerns e.g. young women</p>
RS0331	<p>Policy makers don't want to deal with big alcohol</p> <p>Failure by obstetricians. . Who am I to challenge an obstetrician? They are reluctant to advise women to stop drinking.</p> <p>'I am shocked at the behaviour of obstetricians. Paediatricians seem different.'</p> <p>Difficulty getting an accurate diagnosis</p> <p>Lack of evidence base - trying to argue for priority position for FASD in competition with other conditions</p>	<p>Government – don't want to deal with alcohol industry</p> <p>Medical – failure of obstetricians, paediatricians different</p> <p>Diagnosis – difficulty getting one</p> <p>Research – evidence base lacking compared to other conditions</p>
AP0332	<p>misguided research - minimise fetal alcohol harms</p> <p>lack of support from medical and allied health/social service professionals to government</p> <p>lack of support from key advisors to government</p> <p>fear of the possible scale of the problem and where to start drinking culture.</p>	<p>Research – misguided, minimise fetal harms</p> <p>Medical – lack of support</p> <p>Government – lack of advice from key advisors</p>

Question 9: Who has or holds leadership as the authoritative spokesperson on aspects of this issue? What is it that they are able to say that attracts attention to this issue?		
Participant No. #	Interview data	Coding
BS0101	'many prominent supporters, researchers, clinicians, social scientists, community activists, and tribal and community leaders who champion the causes and prevention programs'	Leadership - many
MD0102	Little leadership	Leadership - little
RS0103	No response	
CH0104	No response	
RS0105	no one nationally, advocacy groups, federal agency literature, a concerted effort	Leadership – no one nationally, advocacy groups
HP0106	No response	
MD0107	<p>Advocates from all areas – congressmen, NOFAS, people from alcohol industry for change will happen in the group</p> <p>We are a crisis oriented society and yet swim in alcohol and alcohol exposure</p> <p>We stigmatize FASD and live in a culture of denial</p> <p>A neurocognitive disability.</p> <p>We look for the 'face' of FASD and fail to understand the global impact of the central nervous system impairment.</p> <p>alcohol treatment programs that are gender specific.</p> <p>The definition of risky drinking is confusing to the lay public and providers.</p> <p>This may sound like a travesty, but in Hu-ley's Brave New World – how do they lower the IQ so that we have enough labourers? This question has some synergy with what we were discussing today.</p> <p>Someone made a metaphorical analogy using tobacco and prisoners of war. Locked in a cell, prisoners are passed smokes under the door and the smokes are covering the stress, not fi-ing the problem. The vernacular in addiction (words like habit, control, dependence etc.) needs discussing and clarifying.</p> <p>There is power in language.</p>	<p>Leadership – all areas, need alcohol industry involved for change</p> <p>Alcohol – swim in it, definition risky drinking too confusing</p> <p>Stigma – culture of denial</p> <p>Diagnosis – it is neurocognitive, focus on face rather than global impact of CNS,</p> <p>Systems and service provision – gender specific treatment programs</p> <p>Medical – power in language, vernacular in addiction needs discussion and clarifying</p> <p>Hu-ley's Brave New World</p>
RS0108	<p>Leadership is crucial for success.</p> <p>In each system...develop commitments for increased prioritization of FASD issues in their system of care. Develop...screening systems, adding diagnostic capacity, developing prevention activities, and inclusion of an FASD component in their system of care.</p>	<p>Leadership –crucial</p> <p>Systems and service provision – increased priority across systems – screening, diagnosis, prevention and care</p>

BP0109	Researchers who speak first hand about animal studies and data from the international research (Mays)	Research – animal studies and international results shared
RS0110	No response	
NG0111	Leadership from various fields	Leadership - many
ET0112	<p>Parents (birth, adoptive, foster and relative care parents) including birth parents who influence by demonstrating beyond rhetoric the potential for recovery and healing.</p> <p>In rare instances in this country, elected officials - Tom Daschle was one such voice but was not re-elected. Established national organizations have had some influence, such as NOFAS and their spokespeople are compelling, such as Kathy Mitchell.</p> <p>Regardless of role or discipline, it is my belief and experience that those who provide clear, thoughtful, proactive information seem to be those who are most effective in attracting attention</p> <p>Engaging others to have a vision, see the potential, empowering them through knowledge to then be effective in their own work, whatever the specific nature of that work and whatever level of influence</p> <p>Depends on the country</p> <p>Different voices - however brilliant and effective as any one person is, any movement whose existence is associated with a single person has a limited future.</p> <p>Framed to consider a collective.</p> <p>No single person, but a collection of diverse voices continuing to talk about different aspects of FASD creates a gestalt, a holistic understanding of the issues and implications.</p> <p>Depending on the audience and developmental level of understanding in the community, different voices have risen above others at different times and in various settings.</p>	<p>Leadership – parents and life stories, elected officials, proactive positions, engage others, visionary, depends on country, voices, collective – a gestalt, dependent on audience</p>
AP0213	<p>A lack of co-ordinated leadership</p> <p>Participants invited to be inclusive but divisions and unwillingness to share resources – underlying loose cannons who can mess things up quickly.</p> <p>No budgets at local levels</p>	<p>Leadership – lacks co-ordination, should be inclusive but there are divisions, unwillingness to share resources, loose cannons who mess things up, no budgets</p>
RS0214	<p>Multiple responses to FASD across different disciplines.</p> <p>FASD Cross Ministry Committee in Alberta has been very effective, at the highest level of government with representation from different ministries who would have some responsibility in responding to FASD, to keep the issues on the table.</p> <p>What works is consistent meetings, considering the impact of FASD across different systems, and</p>	<p>Leadership – many across different disciplines, Canada NW Partnership authoritative. Examples - Clarren, Lutke, Poole, Salmon, NATs</p> <p>Collaboration – cross ministry</p>

	<p>allocating resources to respond to identified needs.</p> <p>The Canada Northwest FASD Partnership is authoritative ... and has been the primary driver in terms of keeping these concerns in the forefront. The work of Dr. Sterling Clarren in collaboration with Jan Lutke has helped move the issues forward nationally and internationally. Nancy Poole and Amy Salmon, co-leads of the NAT on Women's Determinants of Health are also significant leaders, particularly in relation to prevention. The members of this NAT are engaged in outstanding research and community services and supports to women in the interest of prevention.</p>	<p>Alberta, meetings, impact on systems, resources for identified needs</p>
RS0215	Various - number of spokespeople	Leadership - many
AP0216	<p>Linda Reid – important inside government. Linda Reid – important inside government.</p> <p>No one spokesperson, All are engaged. It is not limited anymore.</p> <p>Realization of the impact – it's like a Pandora's Bo-.</p> <p>A lot more discussion about prevention and particularly about treatment for women with addictions.</p> <p>Within this discussion is a little Pandora's box and that concerns what might be done for women with multiple births of exposed children, who refuse to stop drinking, who want to have children. What does it mean is a difficult conversation but one which needs to be held – the economics, the child.</p> <p>No co-ordination. Example, research was rejected by range of organisations, all said the same but separately</p> <p>Alcohol industry less power in Canada. Fund research at Sick Children in Toronto.</p> <p>Government controls alcohol industry but no warning labels.</p>	<p>Leadership –Reid inside government</p> <p>Leadership – no one spokesperson, all engaged, realise impact, treatment for women, women with multiple births of exposed children who refuse to stop drinking – economic consequence and the child</p> <p>Leadership – no co-ordination</p> <p>Alcohol industry – less power in Canada, fund research, government controlled, no labels</p>
RS0217	<p>We might need famous women to tell their stories. Using social networking sites for direct conversations with women.</p> <p>The women at Sheway are among the highest risk women but where the greatest benefits are happening - attend to women's basic needs – accommodation, income etc. Alcohol use is not at the top of your list if these things are going on in your life.</p> <p>Herway House in Victoria is a new program that began with one committed public health nurse but the government is having trouble working out how to give the funding because they prefer to fund a collective group with one NGO managing the funds.</p> <p>Janet Christie is a birth mother who is mobilising a mentoring/coaching program, encouraging mothers with experience to pass on their knowledge to other women in similar situations.</p> <p>Four levels of prevention. The first level concerns public messages; the second, focuses on service providers; the third level is about wrap around services for women; and the fourth, concerns extensive</p>	<p>Women – famous to tell stories, social networking to promote conversations, Sheway example</p> <p>Women – reality – addressing alcohol use not a priority if other things going on in life</p> <p>Government – prefer to fund a collective with one NGO managing funds</p> <p>Prevention – could need a pre-level and a 5th level to ground the work</p>

	<p>post partum support.</p> <p>Focus on Level 2 to build service provider confidence to have conversations with women about alcohol use.</p> <p>Perhaps there is a pre-Level to Level 1 and it might be that there is a Level 5 which will ground it all</p>	
SP0218	<p>Nancy Poole as lead of the FASD Nat on Prevention from a Women's Health Determinants Perspective. - SHE addresses the determinants of health and encourages others to address them</p> <p>Amy Salmon by her involvement in the CanFASD Northwest research Networks-speaks to research that supports policy changes to support women and their children</p> <p>Amy Salmon by her involvement in the CanFASD Northwest research Networks-speaks to research that supports policy changes to support women and their children</p>	<p>Leadership – Poole, Salmon, CanFASD research network</p>
LP0219	<p>There are none...[who are capable] of speaking against the cultural war....the crazy conservative...pandering to lowest common denominator...</p> <p>Fetal alcohol is that unique item which transcends many areas and hit many sacred cows...and the alcohol industry will not tell the truth</p> <p>Social problems needs an active discussion... this is an incremental situation....it will take years because FASD affects basic notions of how to run a criminal law system, how to run school, prisons, job training, notions of disability, degrees of guilt, of blame and shame as opposed to seeing a person</p> <p>'Once we pull one strand, all kinds of fabric tears....and conservatives know it.....no change is ok.'</p>	<p>Leadership – none. No-one can speak against cultural conservatives, FASD transcends, sacred cow</p> <p>Alcohol industry – does not tell the truth</p> <p>Government – social problem, incremental, active discussion – education, justice, job training, disability</p> <p>Stigma and discrimination – guilt, blame, shame</p> <p>'Once we pull one strand, all kinds of fabric tears....and conservatives know it.....no change is ok.'</p>
BP0220	<p>FASlink is the de facto FASD communications network in Canada.</p> <p>FASlink can speak the truth and not be bullied by political correctness because neither the alcohol industry nor government provide funds.</p>	<p>Leadership – FASlink de facto, truth, no funds from alcohol industry or government</p>
ET0221	<p>Government persuaded by professionals who are non-progressive in their practice – suggest plans to benefit own government paid positions</p> <p>No assigned spokesperson</p>	<p>Government – influenced by non-progressive individuals in their practices – propose plans for self-benefit</p> <p>Leadership – no assigned person</p>

SP0222	Can NW FASD research network has the backing of 7 govt jurisdictions in Canada - it is backed by research. So Dr. Clarren. However, even he struggles to keep govt engaged. Each jurisdiction probably has a logical spokesperson	Leadership –Can NW FASD backed by 7 jurisdictions each with own logical spokesperson and research
BP0323	Authority held by academics – Telethon - have credibility & evidence base. Grassroots knowledge is not accepted even though there is practice and wisdom, strategies and interventions	Leadership – authority held by academics – credibility and evidence base, grassroots knowledge not accepted
RS0324	NOFASARD has struggled for a decade trying to attract champions to the cause of FASD prevention without meaningful engagement from those who could change the world for those afflicted with FASD. Unaware of anyone with leadership in Australia to make substantial change - reflects the ignorance, fear of stereotyping and implications around FASD FASD prevention - only NGO and other smaller affiliated groups take on	Leadership – NOFASD struggled to attract champions who could make a difference, no one with leadership to make change
RS0325	Elizabeth Elliott and Telethon Institute. Health professionals lack education and training on this issue and in particular, children with symptoms. No-one is heading down the path of women and drinking which is where my attention is drawn.	Leadership – Elliott and Telethon Systems and service provision – health professions lack education and training, need to attend to issue of women and drinking
MD0326	Different people in different areas: Parent groups NOFASARD, Sue Miers and Elizabeth Russel Aboriginal leaders – June Oscar, Maureen Carter. Lorian Hayes and Emily Carter Researchers (including Elizabeth Peadon, Jane Latimer and James Fitzpatrick) Clinicians and non-clinicians (Carol Bower, Colleen O’Leary and Jane Halliday) Parliamentarians (Jenny Macklin; Sharman Stone; Kenneth Wyatt). Parliament and be influential in legislation.	Leadership – different people in different areas (list of names)
RS0327	Authoritative spokespersons on aspects of FASD include: Sue Miers – attracts attention to the issue through her strong advocacy and by presenting the ‘lived experience’ of parents and carers of people with FASD. Elizabeth Elliott and Carol Bower – are researchers and academics of high standing in the prevention of FASD. They attract attention to the issue in the medical and health community through their advocacy, presenting and publishing research results.	Leadership – authoritative spokespersons in different areas (list of names and areas)

	Potentially in the future, politicians who are taking an interest in FASD, for example, Ken Wyatt, Judi Moylan, Sharman Stone, and Mal Washer. They can attract attention to the issue in Federal	
AP0328	Parents. How do you find me?	Leadership – parents. <i>How do you find me?</i>
SP0329	Fiona Stanley has done a lot of work in Aboriginal communities and in data collection and reporting.	Leadership – Fiona Stanley in Aboriginal communities, research and reporting
RS0330	<p>Articulate parents and family members need to be supported to get their message across about the human aspects of this issue</p> <p>No-one holds it at the moment and it is left to a critical few – obstetricians, midwives and a few researchers and some advocacy groups.</p> <p>There is no strong leadership from more general health areas.</p> <p>It is important to ensure that research cannot simply be ignored as a minor issue or someone else's problem – we need to attach rather than allow detachment from the human element of story or the problem.</p> <p>Watch how we communicate as researchers – if we contribute to a perception of parents who have alcohol problems are bad people or necessarily bad parents – and some researchers have sometimes contributed to this perception – we reduce the likelihood of providing meaningful and effective interventions and reduce the likelihood that people will seek and accept help.</p> <p>We need to humanise the debate – link our research findings to real cases and the impact on individuals, families and the community.</p>	<p>Leadership – no-one, no strong leadership from general health, Left to critical few from health, research, advocacy groups. Articulate parents need support to tell stories</p> <p>Systems and service provision –care re language use about who has alcohol problem, bad parents, bad people</p> <p>Research – link finding to human element</p>
RS0331	<p>Leadership is not limited to a single part.</p> <p>Leadership for families comes from people like Sue Miers and Anne Russell, epidemiology from another group and clinicians are another group – all are singing from the same songbook.</p> <p>Leadership needed in education, in child protection where numbers are high, in justice – need people from these jurisdictions to be more outspoken about their concerns, who have the knowledge, who can articulate the need. Without these kinds of people, concerned individuals will be easily picked off.</p>	Leadership – not limited to single part (list of names) needed in systems where incidence is high
AP0332	Prof Elizabeth Elliott – credibility – highly respected in her field	Leadership - Elliott

Question 10: What will be the new FASD prevention policy directions/initiatives in the future?		
Participant No.#	Interview data	Coding
BS0101	Sovereign tribes developing own policies for communities and people Continued funding for basic research – effects of alcohol on unborn, treatment services, Prevention models and interventions, no systemic understanding of ongoing prevalence Need population based estimates – FASD is currently not easily measured Policy shift from the federal and state level to the tribal level with sovereign tribes Establishing alcohol prevention and intervention policies for their communities and people.	Aboriginal – own policy development, alcohol prevention and interventions Research - funding continued – fetal alcohol and treatment Systems and service provision - prevention models and interventions Prevalence – population based estimates
MD0102	epigenetic research, therapeutics like choline, biomarker in meconium	Research – epigenetics, therapeutics, biomarkers
RS0103	target training at clinics where women are going how to deliver health care in respect to FASD; more interventions on the front line; training programs and support for providers	Systems and service provision – training in clinics accessed by women, FASD health care/interventions, training and support
CH0104	No response	
RS0105	Bills in Congress	Government - Bills in Congress
HP0106	No response	
MD0107	Women will make the difference; matriarchy passing information on in a spiritual way More focus on local issues, on reservations and drinking No country with best practice, not gender and not specific enough Women metabolise alcohol differently, need to consider patterns of drinking and social norms of women and alcohol Alcohol contributes to many health issues 'If not now, when...if not now, when...if not now, when...' 'If I am not for myself, who will be for me? And when I am for myself, what am 'I'? And if not now, when?'	Women – will make the difference, matriarchy, spiritual Aboriginal – local issues, reservations Alcohol - many health issues Women – patterns and norms of drinking 'If not now, when...if not now,

		when...if not now, when...' 'If I am not for myself, who will be for me? And when I am for myself, what am 'I'? And if not now, when?'
RS0108	<p>Effective prevention activities that include the actual women at risk for FASD, not just those that are easily accessible for research studies.</p> <p>Increasing inclusion of a FASD agenda in all service systems with a commitment to increased activities (funding) for these activities.</p> <p>We need to make substantial commitments to intervention across the life span and to increase a focus on the issues that plague adolescents and adults. it will be important to increase intervention for adolescents and adults, not just early intervention, if we are to reduce the burden of FASD.</p> <p>New diagnostic criteria relevant to adolescent and adult outcomes – diagnosis will not involve growth or facial features.</p>	<p>Women – effective prevention activities for actual women at risk, not just those easily accessed for research</p> <p>Systems and service provision – FASD agenda in all plus increased programs, intervention across lifespan</p> <p>Diagnosis – new criteria inclusive of adolescents and adults, not involve growth or facial features in the assessment</p>
BP0109	I believe the no known safe amount will continue.	Alcohol – no safe amount
RS0110	No response	
NG0111	<p>Improved and expanded surveillance</p> <p>Research on mechanisms of alcohol induced defects and biomarkers</p> <p>Uniform, scientifically-grounded definition of the full spectrum of alcohol-related birth defects, including PFAS, ARND, ARBD</p> <p>Enhanced FASD screening, and screening for women of childbearing age using alcohol</p> <p>Longitudinal studies</p> <p>The recognition of FASD under all federal disability-related benefit programs and in all relevant classification and eligibility systems</p> <p>Education for medical and allied health professionals</p> <p>Education for school systems, administrators and teachers, law enforcement, the courts and the correctional system</p> <p>Promotion of a continuum of care for children and adults</p> <p>Implementation of interventions</p> <p>Enhanced quality and availability of services</p>	<p>Research – surveillance, mechanisms of alcohol induced defects and biomarkers, longitudinal across lifespan</p> <p>Diagnosis – scientifically grounded definitions of complete spectrum</p> <p>Government – disability financial support</p> <p>System and service provision – education in health, education, administration, law, continuum of care for children/adults, interventions, quality and availability of services</p>

ET0112	<p>‘No single prevention policy or activities can or should attempt to address the many historical, cultural, intellectual, personal and professional obstacles that exist. Each should be informed by their existence.</p> <p>Multiple simultaneous, sustained activities over a minimum of fifteen years would then be created and implemented that recognize the developmental stages of shifting thinking and achieving prevention.</p> <p>The challenge is to assure conceptual consistency, using a shared language to further cross-cultural and –discipline.’</p> <p>Creation of a cultural context in which prevention is possible. identifying community partners, articulating values, beliefs and goals to assure congruence</p> <p>planning for sustained implementation from many directions simultaneously</p>	<p>Government – no one policy can accommodate historical, cultural, intellectual, personal and professional obstacles, needs time to shift thinking, create conceptual consistency, shared language, cross cultural discipline</p> <p>Collaboration – create cultural context, congruence, partners who can articulate diverse values, beliefs, goals</p>
AP0213	<p>Parent led formal national organization is required because intervention and support ARE prevention.</p> <p>PhD (academic) versus parent and there is no conversation there is a lack of meaningful communication b/t the two groups and that it is essential if anything is to get done</p> <p>The 100% preventable message might have been a mistake. It shows a basic lack of understanding of addiction and the social determinants of health and is far too simplistic</p> <p>We need to refocus on the social determinants of health and re-focus on the primary health messages and be much more specific as to what the message needs to be for what group of women and under what circumstances</p>	<p>Advocacy – parent led national organisation, human story, less competition between academic and parent, meaningful communication.</p> <p>Women – 100% message might have been a mistake. Focus on social determinants of women’s health.</p>
RS0214	<p>Identification of inter-professional collaboration and streamlining responses to families across systems. Inter-sectoral collaboration is critical in responding to the complexity of FASD and no one discipline alone can respond to these concerns, so greater efforts at collaboration, which includes sharing funding resources should be considered.</p> <p>Access to diagnosis should also be developed in policy for both children and adults, and those in rural regions should be afforded similar access to resources. There should not be a disadvantage to those in rural regions.</p> <p>A model of intervention with high risk families, mothers, fathers and children that incorporates the best of differing responses from professional service systems in support of inter-sectoral, cross-disciplinary responses.</p> <p>Greater focus on the role of fathers as research and policy is very limited.</p> <p>Post secondary education in the health professions, social work and psychology should infuse</p>	<p>System and service provision - streamlining responses to families,</p> <p>Collaboration - inter-professional to respond to problem complexity, shared funding</p> <p>Diagnosis – improved access for all, rural communities</p> <p>Research - inclusion of fathers</p> <p>Education - health professions, social work and psychology should infuse courses on FASD/Disability concerns in their curriculum, a</p>

	courses on FASD/Disability concerns in their curriculum. The lack of preparedness of post secondary graduates in the human services to work with this complex a problem needs to improve. Although efforts exist in the interest of this education it is not consistent, leaving the venue for further education to conferences and workshops. Given the rapid growth of disabling conditions, and awareness of the impact on society a disability paradigm must be considered as essential to post secondary education for those entering the helping professions.	disability paradigm must be considered as essential
GP0215	I do think that mentoring programs such as PCAP will continue to lead the way in FASD prevention, particularly for those most at risk of having children affected by FASD.	Women - PCAP
AP0216	Champions are individuals well placed to move the agenda in strategic places Family stories need to be told.	Advocacy – champions, family stories
RS0217	It is the use of ‘subtle’ messages, enough to promote individual women to think about the choices they might make in their own lives. Creating a broader and broader consensus. Changes keep moving us forth. The government needs to have policies which solidify into the strategic plan and open enough to be able to make a shift if needed. One of the women I interviewed recently about Healthy Choices for Women said her involvement was one of the best experiences of her 30 years in work - the availability of a vision and an endorsed provincial strategic plan; committed people in attendance from the Health Authority; and the presence of Christine Locke and Nancy Poole representing clinical and research knowledge.	Women – subtle messages which encourage thinking Policy – broader consensus Government – policies to solidify the strategic plan and flexible to accommodate shifts as necessary
SP0218	I hope that there is continued emphasis on addressing the broader determinants of health for women. The programs that are developed need to have client input on what works for them; they need to be client centered, non-judgemental and respectful. They need to use a harm reduction philosophy. More research done on the effects of cortisol/stress on the developing fetus - useful in both developing practice in the treatment provided to women and in the prevention of disorders in the fetuses.	Women – emphasis continues re addressing broader determinants of health, input into program development-client centred, non-judgmental and respectful – harm reduction approach Research – effects of cortisol
LP0219	A way to train ‘FASD’ criminals...not in prison More analysis to get better info on prevalence More personal, less shame and blame education words for women	Systems and service provision – training for offenders outside prison Research – better information on prevalence,

		Stigma/discrimination – less shame/ blame words for women
BP0220	<p>‘I am tired but not yet dead, so I continue to battle... I have spent a lifetime trying to save the world, only to finally realize that the world does not want to be saved. I must be a slow learner.’</p> <p>High doses of Folic Acid (1000 ng daily) during pregnancy can block much of the neurological damage caused by alcohol.</p> <p>Awareness of the lifetime challenges and costs of FASD that can be 100% prevented will grow and become part of the education system.</p> <p>Humanity has written about this issue for 3,000 years, yet the term ‘Fetal Alcohol Syndrome’ is only about 25 years-old and FASD about 10 years.</p> <p>Perhaps the beverage alcohol industry will be taxed and sued for the damages they cause and booze will become too expensive to binge. Sip maybe, but not binge.</p> <p>The ethical question is whether to require it to be added by the booze manufacturers.</p>	<p>Advocacy – individual</p> <p>Medical – folic acid</p> <p>Cost – lifetime challenges</p> <p>Alcohol industry – sued for damages</p>
ET0221	<p>Realize that supporting women in prevention and treatment of addictions is the first step in preventing FASD.</p> <p>Treating women respectfully and with acknowledgement of their journey in life will enhance disclosures of prenatal substance use.</p> <p>Providing women with medically accurate information of the possibilities is essential to prevention strategies.</p> <p>Consistency of addressing women will be critical to success locally and on a global level.</p>	<p>Medical – treatment for women, respect their life experience, improve settings for disclosure</p>
SP0222	<p>Know what needs to be done, can’t wait for government to accept this premise and act or go ahead and do the work in community minded ways</p> <p>Why is there nothing new on FASD at conferences? Because ‘we don’t get the old stuff yet.’</p> <p>Key in community economic development – strong viable communities one at a time</p>	<p>Government – can’t wait for government to do what is required</p> <p>Advocacy – strong local viable communities</p>
BP0323	<p>A realisation that funding is being wasted – the funds going on supporting people affected by FASD when we don’t now people are affected, are not working.</p> <p>We need to fund proper programs and prevention that instead of setting people up for failure, they will empower and provide people with FASD a solid foundation.</p> <p>An 1800 number</p> <p>We know what is needed but getting funding to put this all together is not easy.</p> <p>a National FASD Coordinator.</p>	<p>Government – a national peak body and co-ordinator</p> <p>Funding – wasted and set people up for failure, need to invest in proper programs</p> <p>Systems and service provision – not working, system needs to adapt to</p>

	We need a peak body which is funded so that together we can plan for the future - work needs to happen quickly, more focused than the Taskforce set up by Health and Ageing Typically, the individual has to fit in the system and IQ is not a suitable measurement as many people affected by FASD have normal IQ's.	meet needs of the individual
RS0324	Legislative action– nutrient and warning labels, enforced stewardship in alcohol marketing, etc. Follow the US and Canada guideline and diagnostic clinics but for the moment we are stagnating. A scientific breakthrough that has the world sitting bolt upright, our prevention efforts will remain invisible. Care to structure in a FASD Strategic Framework to instruct bureaucrats on how to proceed. Champions from media, medical specialties, research groups, parents and carers, as well as support groups, change will eventuate.	Government – labels and alcohol industry regulation, strategic framework to guide bureaucrats Diagnosis - follow international guidelines Research – a scientific breakthrough Advocacy – champions and support groups
RS0325	Training in medical schools The pregnant mother must be living in a safe environment. She must be able to tell herself 'I have to plan to be healthy before I have a baby.' Massive public health prevention project Zero tolerance messages – 'no amount is safe' and family planning. Good national planning Proactive rather than reactive programs	Workplace training – medical schools Women – must be safe to then plan to be healthy National campaign – zero tolerance message Government – good planning - proactive
MD0326	Ta- alcohol properly (on a volumetric basis) and limit access to full strength alcohol. In high risk communities, provide support through legislation and then enforce that legislation. Alcohol labelling - to raise community awareness. We need a National Alcohol Awareness Campaign Target pricing and accessibility. Early education in schools targeting young women A comprehensive approach to supporting healthy pregnancies. 'One of the great things to happen was the leadership shown by Aboriginal people from the Fitzroy Valley. This group lobbied the WA Licensing Board and were successful in limiting sales of full strength take-away alcohol and hence alcohol consumption in those communities. This is mentioned by Mick Gooda (Australia's Aboriginal and Torres Strait Islander Social Justice Commissioner) in his Social Justice Report for 2010. An entire chapter is dedicated to	Alcohol- range of measures – volumetric ta-, pricing, labelling, legislate and enforce alcohol restrictions to support high risk communities, national campaign (example Fitzroy Valley) Women – early education of young women Medical – comprehensive approach to support healthy pregnancy

	issues relating to alcohol misuse and identification and diagnosis of FASD and demonstrates the impact of lobbying by this community.	
RS0327	<p>Volumetric taxation on alcohol;</p> <p>Labelling alcohol products - a suitably worded warning message about the risks of consuming alcohol while pregnant be mandated on individual containers of alcoholic beverages and at the point of sale for unpackaged alcoholic beverages, as support for ongoing broader community education.'</p> <p>Recognition of FASD and legislation for FASD to be in the Disabilities Act;</p> <p>Developing a screening and diagnostic instrument for FASD that is implemented and sustained by Australian health professionals</p> <p>A call for action to form a national organisation for the prevention of FASD</p> <p>Establish national minimum data sets for recording and reporting alcohol consumption in pregnancy</p> <p>Establish national minimum data sets for recording and reporting diagnoses of FASD</p>	<p>Diagnosis - FASD recognition as a disability, screening and diagnostic instrument implemented and sustained</p> <p>Alcohol- range of measures – volumetric tax, labelling,</p>
AP0328	No response	
SP0329	<p>Public education and powerful messages</p> <p>'Our prisons are full of individuals with brain damage and they are impetuous and disinhibited. They probably have frontal lobe damage.'</p> <p>'I saw a family from South Australia. The fostered children were assessed to have FAS and Munchausen's syndrome respectively. The foster parents drove all the way to Brisbane to get help and an opinion.'</p> <p>There is a proven overlap between ADHD and FASD. 75% of children diagnosed with FASD also have ADHD</p>	<p>Future –</p> <p>Public education</p> <p>Diagnosis – understand co-occurring diagnoses</p>
RS0330	<p>FASD is not just an issue for a few women in a few communities. It is an issue for the whole community</p> <p>Risk is if we allow a continuation of alcohol problems as being an issue for only a small number of odd or perhaps 'bad' people.</p> <p>Need to invest in population level, such as affecting levels of alcohol consumption, as well as individual interventions, such as brief interventions.</p> <p>The reality is we won't prevent all of FASD.</p> <p>Need to focus and adopt the principles of public health – 1st, 2nd & 3rd level prevention.</p> <p>Engage the community in working out how it should be prevented; not just assuming a handful</p>	<p>Future –</p> <p>A whole of community issue, overcome denial that it is only linked to others;</p> <p>Do more in reducing levels of alcohol use in general population;</p> <p>Focus on principles of public health prevention</p> <p>Engage with community and not</p>

	<p>of bureaucrats will know how to respond.</p> <p>Much better information for parents in the community</p> <p>Need to communicate that the risk is dose dependent.</p> <p>Need to communicate that early interventions will have better impact than delayed interventions.</p> <p>At an individual level we need regular intervention prior to pregnancy and through obstetrics and early care.</p>	<p>hand over to bureaucrats</p> <p>Better community information and risk as dose dependent, early intervention is better as is intervention before pregnancy</p>
RS0331	<p>Fifty per cent of women consume alcohol in pregnancy and 95% of these women won't be Indigenous women.</p> <p>They knew about FAS in the 1980's but no-one asked about alcohol use.</p> <p>Most women want the best for their children and maybe some of the children born would not have had the problems in life that they have had to deal with.</p> <p>There is a lot of work to be done - have to show the burden like in prisons – the percentage affected.</p> <p>Health says we need more resources to manage.</p> <p>'I said to my mother, thank goodness you never drank or where would I be, how would I be coping. I choose not to drink but it is astounding how much pressure is applied to taste this or that wine. Someone was telling me about a baby shower she attended and many of the women were pregnant. Ten bottles of champagne were provided and all were drinking. There was an argument that the champagne was low alcohol. The person telling the story had to leave as she could not stand to watch pregnant women drinking alcohol the way they were.'</p> <p>Take the mystery out of FASD</p> <p>'I was amazed at a Canadian conference when people affected by FASD were a voice.'</p> <p>A strong community voice.</p> <p>FASD is not an Indigenous issue.</p> <p>If it were possible to screen all women, the numbers in the Aboriginal communities would be very low by comparison.</p>	<p>Women – 50% consumers and if screened, 95% will not be Indigenous, it is not an Indigenous issue</p> <p>Women – want the best for their children, a lot to deal with in life</p> <p>Medical profession – knew risks but did not tell</p> <p>Future – show the burden like among prisoners, demythologise FASD, a voice for those who live with the problem,</p> <p>Funding - more resources</p>
AP0332	<p>Short term – minimal progress. Long term – gradual understanding of the true extent of the issue –community awareness raising initiatives. Eventual outcome – still a long way off – recognition and understanding of the risks to the community of alcohol consumption including its effect on the unborn child similar to the understanding pertaining to risks associated with tobacco, thalidomide etc.</p>	<p>Future – short term minimal progress, longer term – the scope of the problem, public awareness increase, recognition of link with alcohol consumption</p>

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